ANGLIA RUSKIN UNIVERSITY

WHAT WORKS: RESEARCHING SUCCESS IN PARENTAL MENTAL HEALTH AND CHILD WELFARE WORK

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ANGLIA RUSKIN UNIVERSITY
ABSTRACT

FACULTY OF HEALTH AND SOCIAL CARE
DOCTOR OF PHILOSOPHY

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This study investigates success in parental mental health and child welfare work. Research has established the potential direct and indirect impacts of mental illness on parenting, the parent–child relationship, and the child, and the extent to which this poses a public health challenge. Problems with how adult and children's services understand and deliver support to parents with mental health problems and their children have also been identified. In contrast, there has been little research about how parents with mental health difficulties and their children can be supported successfully. '*What works',* or what constitutes *success* in parental mental health and child welfare work is missing from the literature. This study aims to begin to address this gap by providing an original contribution to conceptualising and evaluating success in parental mental health and child welfare work.

This is an exploratory study, and as such covers a diverse population, i.e. different family members, different cultural and ethnic backgrounds, parents with different diagnoses, and statutory and voluntary sector agencies. The main issue here is to cover diversity; in terms of exploring different opinions of success – both in outcomes and processes – rather than to ensure applicability of the findings to all families in which there are parents experiencing mental illness.

An interpretative approach was chosen for the study (within that data) to explore these issues. This was obtained by undertaking a multiple embedded case study methodology (Yin, 2003) with 12 families and their key workers from community mental health, children's social care and the voluntary sector. Data collection was undertaken in three stages: individual interviews with parents, children and the professionals who support them; a review of the agency case files kept about the same families; and three focus groups. Participants were asked to identify successful situations that had occurred in each case study family during the 18 months prior to interview and give details about why these situations worked out well. The focus groups were convened to discuss the emerging findings from the first two phases of data collection.

An examination of emerging themes, and the interplay between themes, gives insight into the shared ideas about *what works* and the shared methods and practices that are associated with successful outcomes. On the basis of these similarities, the findings offer a contribution to knowledge and practice about a mode of working which seems to make it possible to succeed in helping families previously considered beyond help. What is more, the practitioners also benefit from the helping relationship in this context. ***Key words:*** *Mental health; parents; children*

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CHAPTER 1 – INTRODUCTION TO THE RESEARCH

Parents with mental health problems and their children are a group of families that health and social care services find it difficult to help in an acceptable, accessible and effective manner. However, some families faced with multiple adversities and deemed high risk of suffering negative impacts are supported successfully, despite the potential difficulties and the barriers described in the literature. Exploring what constitutes success and the components needed to achieve success from the perspective of parents, children and practitioners has not previously been researched. This is the area to be explored in this study.

Whilst this study does not suggest that all children who have a parent with a mental health problem will be impacted negatively as a result, there is a large and increasing body of research that highlights the potential of such an impact of parental mental health problems on children, as well as the needs of adults with mental health problems in regard to their parenting (Webster, 1992; Stiffman et al., 1988; Hugman & Phillips, 1993; Cox, 1993; Darton, et al., 1994, Cleaver et al., 2012). Public and professional attention has also focused on the dilemmas and isolation of young carers and the difficulties in identifying who they are and how to meet their needs (Elliot, 1992; Dearden & Becker, 2004). Young cares are defined as children under 18 who provide significant personal and/or emotional care to their parent(s) (SCIE, 2005). This study will be considering all children in families with parental mental health problems, and not only young carers, although there are important points to be made about this group.

Working in either adult mental health or children and family social care services can be challenging. Both areas are highly emotive, they attract high levels of media attention and criticism, and staff can be wary of stepping outside of professional boundaries. Breaking down these professional barriers is as important as addressing the stigma that exists in accessing services for parents and children. It has become custom and practice to talk about barriers to successful practice, rather than exploring what happens when families are supported successfully.

Policy and research recommendations focus on making improvements in inter-agency collaboration and workforce development initiatives to increase and improve the knowledge, skills and attitudes of managers and practitioners. Links to how these changes will actively achieve positive change for families are rarer.

The focus of this research is therefore to learn from the successes of twelve families who have experienced '*success*' and the staff that have supported them and to share this learning with others.

CHAPTER 2 – THE CONTEXT OF THE RESEARCH

INTRODUCTION

This chapter sets out the national and local context in which the research takes place. It gives a description of the policy context in England as it relates to parental mental health and child welfare work, describes the research sites and the organisations taking part, and concludes with an account of my prior experience and knowledge of the topic being research and my relationship with the organisations taking part.

THE POLICY CONTEXT

This section of the chapter critiques how adult and children's policy and guidance addresses the linked issues of parental mental health and child welfare. It considers the government's intent to incorporate a *think family* perspective across policy areas and examines some of the cross government's whole family initiatives, including the *Sure Start* and *Family Intervention Projects (FIPs)* set up to support families and promote the health and wellbeing of children.

The policy divide

Policy generally utilises the concept of parental mental health problems, rather than distinguishing between mothers' and fathers' mental health needs, and research about parental mental health has largely focused on mothers, resulting in a gap in our understanding of the individual experiences and needs of different family members (Stanley & Cox, 2009; Parker, et al., 2009; Morris & Wates, 2006*).*

Driven by the child poverty, public health and social exclusion agendas, policy makers are evidently concerned about how the gaps between children's and adult services do not reflect the extent to which children's and adults' needs are interlinked. This has resulted in a number of policy injunctions to look beyond service divides; most of which have been directed at adult services. This reflects research and other literature, which emphasises that professionals working with adults can fail to recognise their parenting role and the needs of their children (Parker, et al., 2008). However, there is an equal case to be made for policy to

identify and make use of research evidence which examines the capacity of practitioners in children's services to identify and respond appropriately to manifestations of mental illness in parents (Stanley & Cox, 2009; Kearney et al., 2003; Shepperd, 2001; SCIE, 2009). This is largely missing in children's policy. Not paying attention to all of the available evidence can result in an incomplete picture of what is happening and a distorted view of where improvements need to be made.

Working together

Risks to children emerge as the strongest driver to improve inter-agency communication, collaboration and integration and these concerns have exerted a strong influence on policy, planning and service structures (Parker, et al., 2009; Morris, et al. 2006; Stanley & Cox 2009). The belief that welfare services could be improved if agencies worked together more efficiently has been a consistent theme of policy over the past 40 years. In a systematic review of the evidence about factors that promote and obstacles that hinder joint working (Cameron & Lart, 2003), the authors concluded that while research had a lot to say about the process of joint working, very little attention had been paid to exploring the effectiveness of this approach either for service users and carers or for the organisations providing services. An update of this review was carried out in 2012 (Cameron, et al. 2012). Taken together, the findings provide a 30-year overview of UK-based evaluations of joint working in health and social care. The findings demonstrate some tentative signs that progress has been made since the original review and that it is now possible to demonstrate some positive outcomes for users of services, carers and service organisations. However, they conclude the evidence base about joint working is patchy and more research is required to sharpen and broaden our understanding of these outcomes. In the fields of adult and children's health and social care a variety of strategies have been introduced to encourage or direct agencies to work together and examples of these can be found in the remaining sections of this part of the chapter.

Attempts have also been made to target policy recommendations more specifically to situations or organisations that have not responded sufficiently to previously broad brush recommendations about improving inter-agency collaboration. An example of this can be found in *Working together to safeguard children – a guide to inter-agency*

working to safeguard and promote the welfare of children (DofE, 2010) which sets out how individuals and organisations should work together to safeguard and promote the welfare of children. The guidance, first published in 2006 and updated in 2010, includes new emphasis and recommendations specifically aimed at meeting the needs of families where there are parental mental health problems. For example, in chapter 3.71 which sets out the membership and requirements of membership for Local Children's Safeguarding Boards (LSCBs), it says:

> 3.71 *The local authority should ensure that those responsible for adult social services functions are represented on the LSCB, given the importance of adult social care in the context of safeguarding and promoting the welfare of children. Similarly health organisations should ensure that adult health services and in particular adult mental health, adult drug and alcohol services and adult disability services are represented on the LSCB.*
> *(*DCSF, 2010)

Previously, the guidance set out the membership for LSCBs to include adult mental health representation, but this was not often adhered to. As a result, there was no representative from adult mental health; it was delegated to someone without the seniority to actively participate, or sometimes it was delegated to a CAMHS member on the board, on the basis that they worked for the same mental health trust (SCIE, 2009). The recommendation in the new guidance firmly singles out organisations that have been previously slow to comply but it remains to be seen if this has the desired effect for LSCBs across the country.

<u>Mental health policy</u>

No health without mental health: a cross-government mental health outcomes strategy for people of all ages (DH, 2011) has the dual aims of improving the mental health and wellbeing of the population and keeping people well; and improving outcomes for people with mental health problems through high-quality services that are equally accessible to all. It recognises that our social circumstances, adverse life events, relationships and inequalities are major factor in determining all of our mental health and wellbeing. It also recognises that many services are already in place that aren't generally considered mental health services, but which could help promote

public mental health and wellbeing and prevent future problems across the lifespan and inter-generationally. For example, mother and toddler groups, school health initiatives that promote self-respect or better relationships, and reading initiatives which improve literacy, social skills and self-esteem. The focus on prevention, maintaining good mental health, and promoting recovery in the context of a whole population mental health strategy is particularly relevant to parents with mental health problems and their children, as is putting mental health promotion as a theoretical framework in which the centre of public health efforts. The potential of mental health promotion as a theoretical concept that can aid our understanding and evaluation of parental mental health work is explored in the *Literature* chapter of this thesis (page 28).

Adult services policy

Think Local Act Personal (TLAP, 2011) builds on Putting People First (DH, 2007) which sets out the government's commitment to independent living for all adults. It includes in its intentions that individuals should be supported to sustain a family unit which avoids children being required to take on an inappropriate caring role; family members and carers should be treated as experts and care partners; systems should support integrated working to include parent carers; and identifying and addressing concerns about children's welfare. It also claims that adult social care will take responsibility for championing local action to tackle the stigma faced by people with mental health problems. The aim of Putting People First is to enable people to live their own lives as they wish; confident that services are of high quality, are safe and promote their own individual needs for independence, wellbeing, and dignity. *Personalisation,* a key element of the Putting People First agenda, challenges the traditional notion that staff and managers know what is best and determine what care and support someone should have. It means thinking about care and support services in an entirely different way, starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. However, perceptions about risk continue to compromise access to, and uptake of, options like direct payments for people with mental health problems (Carr & Robbins, 2009), despite evidence that people with

mental health problems may have the most to gain from increased choice and control over their support arrangements (Glendinning et al., 2008).

Children and young carers

Every Child Matters: Change for Children (DfES, 2003) sets out the national framework to build services around the needs of children and young people in order to maximise opportunity and minimise the risk of poor outcomes. The Children Act 2004 provides the legislative foundation for whole-system reform. It outlines statutory duties and clarifies accountabilities for children's services. It acknowledges that legislation by itself is not enough: it needs to be part of a wider process that can only be delivered through local leaders working together in strong partnership with local communities. Every Child Matters identifies five outcomes that are key to wellbeing in childhood and later life:

1. Being healthy
2. Staying safe
3. Enjoying and achieving
4. Making a positive contribution
5. Achieving economic wellbeing.

The aim is to improve those outcomes for all children and to narrow the gap in outcomes between those who do well and those who do not.

There is no specific legislation directly addressing the needs of children and young people as carers, although they have legal rights both as 'children' and as 'carers'. Primarily, provision for young carers is made under Section 17 of the Children Act 1989, where they are designated as 'children in need' by virtue of the potential effects of caring on their 'ability to thrive'. The UN definition of the 'rights of the child' also clearly indicates the moral and legal need to acknowledge the human rights of children and young people as 'non-adults'. Both can be problematic, however, as the definitions may not adequately provide for the needs of children and young people as 'carers'. The Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004 apply to all carers, irrespective of age, and provide the statutory framework for an individual assessment of carers' needs in addition to an assessment of the needs of those in receipt of care.

Whole family approaches — Sure Start, Family Intervention Projects, Family Nurse Partnerships, Troubled Families and Community Budgets.

In 1998, the *Independent inquiry into inequalities in health* proposed three priorities for the focus of sustained effort to tackle entrenched inequalities in the UK, the first being families with children. Specifically, it was noted that parents in disadvantaged circumstances might need family support beyond that provided by universal services, in order to protect their children from adverse impact (Acheson, 1998). This opened the door for a range of initiatives with the aim of support families and promoting the health and wellbeing of children including Sure Start Programmes (HMSO, 1998) and subsequently, Children's Centres, Extended Schools, Family Intervention Projects and Family Nurse Partnerships (Cabinet Office, 2007; DCSF, 2007; DH, 2008d; HM Government, 2006; Home Office, 1998). However despite the policy intentions many programmes have failed to engage with families with multiple difficulties.

The Sure Start Programme and the development of Children's Centres brought together early education, childcare, health, employment and family support services under one service. Originally targeted at the poorest families in England (Home Office, 1998), Sure Start has been one of the most substantial social reform initiatives for families embarked upon in recent years. However, successive evaluations have had to acknowledge that greater effort is required to reach the most vulnerable households and in particular parents with mental health problems (Allnock, et al., 2006). A review by Tunstill et al., (2005) examining how children's centres could reach the most disadvantaged families failed to explore the potential of involving and working together with adult services to identify and reach families. Similarly, guidance from DH (2007a) on delivering health services through *Sure Start Children's Centres* did not include mention of adult mental health services.

Family Intervention Projects (FIPs) were first introduced in England as part of the implementation of the Respect Action Plan (Home Office, 2006), with the dual purpose of providing direct support to anti-social families and alleviating adverse impacts in the local community. FIPs work with families in residential, community-based and outreach settings, are multi-agency in approach and typically adopt what

are referred to as ‘assertive’ and ‘persuasive’ styles of working with families. Each FIP should have access to a nominated health professional. However, the national evaluation of the first wave of 53 FIPs (White, et al., 2008) found that many did not, and that the involvement of health services needed to be improved on a range of fronts; in particular multi-agency working and referring families to FIPs. Contact and information sharing between health and FIPs was generally lower when compared with all other agencies apart from child care social services, and there was a perception that health services were reluctant to attend meetings and work jointly. The evaluation did not report on the involvement of mental health services, even though one study reports that 80per cent of parents and children in families in contact with FIPs had poor health and mental health problems (DCLG, 2006). Exceptions were noted with regard to some Child and Adolescent Mental Health services (CAMHS).

The Family Nurse Partnership model is a service delivered by nurses and consists of home visits and intensive support to young and vulnerable first time parents. First announced as part of the Government’s action on social exclusion (HMG, 2006), DH and DCSF have jointly funded 30 such projects (Cabinet Office, 2009). Preliminary evaluation of these initiatives report on the difficulties in identifying and supporting parents with mental health problems, and of joint-working between child and adult services (Barnes, et al., 2008).

The coalition government’s Troubled Families initiative (2011) is about families who experience multiple social, health, and economic problems. The government estimate is that there are up to 120,000 such families, which at times make very high demands on local services but which can still experience poor outcomes. Troubled Families are, we are told, typically: involved in youth crime or anti-social behaviour; have children who are regularly truanting; have an adult on out-of-work benefits; and cost the public sector large sums in responding to their problems. The Troubled Families team, based at the Department for Community and Local Government (DCLG) are working with local authorities and their partners to drive forward the program which uses intensive intervention to support and challenge families. The approach builds on the work of the Family Intervention Projects (FIPs). There has been criticism about the Troubled Family policy as it not yet clear who these families

are. The government estimate there are 120,000 troubled families across the country but in October last year only 6.9 of this total number had been identified by local authorities. The main problem many councils encountered was that the 120,000 figure was based on a piece of secondary analysis of the 2004 *Families and children's study,* which is now out of date, and the calculation has a potential margin of error larger than the figure itself (200,000). Whilst some use may come from local councils gathering information about families in their area that are troubled this seems back to front, designing the solution before there was up-to-date information on exactly what the problem is. So it is hard to see who exactly will benefit from the resources attached to Troubled Families but it is clear that the majority of families experiencing parental mental health problems will not be eligible.

The government's plans for Community Budgets (Piloted in April 2011) is an approach to tackle barriers to shared funding. Community Budgets seek to generate a context in which whole-family approaches can flourish. At the time of writing, it is too early to judge their success in doing so.

PROFESSIONAL GUIDANCE

Guidance aimed at adult or children's services varies in the degree that it incorporates a family perspective. To illustrate this point three examples of guidance are set out below. The first is *Refocusing the Care Programme Approach (*CPA*) – policy and practice guidance* (DH, 2008), which is the standardised care management and recording framework used by community and in-patient mental health services. The second is the *Think child, think parent, think family – a guide to parental mental health and child welfare work* (Diggins, 2009) which is the first cross-cutting guidance aimed at adult and children's health and social care professionals about this topic. The third example considers a review of guidelines produced by the National Institute of Health and Clinical Excellence (NICE), on relevant guideline topics' coverage of issues related to parental mental health.

<u>Refocusing the Care Programme Approach (CPA) – policy and positive practice guidance (DH, 2008)</u>

Refocusing the Care Programme Approach (CPA) – policy and positive practice guidance (DH, 2008) introduced a number of changes to the CPA. It stated that the

needs of key groups, including parents, should be fully explored to make sure that the range of their needs are examined, understood and addressed when deciding their need for support. This is the first time that the CPA process explicitly recognises the needs of adults as parents. It was hoped (by those of us following these changes) that by specifying parents in the revised CPA and the need to pay attention to the needs of their children, would lead to more family friendly service eligibility criteria that would enable parents who had not previously met the criteria to now do so. In practice this has not happened, and very few managers and practitioners (when consulted) had noticed this inclusion or thought about interpreting the guidance in this way (SCIE, 2009).

SCIE's *Think child, think parent, think family: a guide to parental mental health and child welfare* (Diggins, 2009)

SCIE's *Think child, think parent, think family a guide to parental mental health and child welfare* (Diggins, 2009) makes recommendations about what needs to change to improve service planning, delivery and practice, with the aim of improving the health, wellbeing and life chances of families affected by parental mental ill health. A number of systematic reviews and a survey of existing practice by health and social care services in mental health and children and family services in five sites in England were undertaken to provide the evidence to underpin this guide (Parker et al.,2009; Stanley et al., 2009; SCIE, 2009). An advisory group of key stakeholders was recruited including parents and young people to contribute to the review and guide development. A synthesis of the reviews found strong supporting evidence about the potential impacts of mental illness on parenting, the parent-child relationship and the child and about the barriers to effective practice and outcomes for families. Evidence about what works for families was much harder to come by. A national consultation exercise was undertaken on the draft guidance before final amendments and publication in July 2009.

Guide dissemination, implementation and evaluation was supported by: a joint SCIE, DH and DfE dissemination and implementation plan; new training resources and a series of Social Care TV programmes all linked to the guidance. Five pilot sites in England and the six Trusts in Northern Ireland were recruited to pilot the guidance and the learning from this is shared in an update of the guide published in 2011 and

a separate report (Roscoe, H., 2011). The final evaluation (Roscoe et al., 2012) findings are largely about process outcomes due to the insufficient timeframe to adequately assess family outcomes. Some examples taken from the evaluation about lessons about practice and remaining challenges or intractable issues are as follows:

- Developing partnerships with, and capacity in, the voluntary sector created opportunities for families to access support away from the high eligibility thresholds in the statutory sector.
- Joining the project to initiatives for young carers, general parenting, and substance misusing parents created practical links and avoided duplicated efforts.
- Both the Common Assessment Framework (CAF) and Team Around the Child (TAC) seemed to help people *think family*. Several sites sought to expand this to a Team Around the Family, also including professionals working with the parent.
- Liaison workers were recruited to work between adult mental health and children's services.

Remaining challenges*:*

- There was some promising exploration of the potential for the CAF to be used to support integrated working, but there was less exploration of the possibilities offered by the Care Programme Approach (CPA) used in mental health services.
- Family thresholds were not explored as a means of promoting earlier interventions.
- Information sharing at a strategic and case-specific level remained problematic, despite some advances in Birmingham in triggering inter-agency liaison.
- The focus on improving joint-working between key health and social care departments often contributed to less engagement with GPs and schools.

(Roscoe et al., 2012)

Guidance produced by NICE for mental health services

The third example is taken from an unpublished review undertaken by SCIE as part of their guidance development programme for *Think child, think parent, think family* described above. The review looked at guidance produced by the National Institute for Health and Clinical Excellence (NICE) on relevant topic's coverage of issues related to parental mental health. The review was undertaken to help to establish how far guidance assisted professionals in parental mental health and child welfare work. The review found at that time 25 pieces of NICE guidance had potential relevance (e.g. guidelines on schizophrenia) of which seven mention parental mental health issues, mostly as a single minor point. A second group (a further eight) could include parental mental health problems without mentioning the issue, via phrases such as 'disadvantaged background'. A third group of guidance (seven) is on relevant topics but does not mention or imply parental mental health issues. The level of coverage of parental mental health issues was so low that the little that was found can only be related to the impact of mental health problems on: parenting, family life; the parent-child relationship and the child (SCIE, 2009). As an illustration, there appears to be no guidance in the NICE *Schizophrenia guideline* (CG1) directed towards parents with mental health problems and in the *Borderline personality disorder* guideline, although the word 'carer' appears 85 times within the final document, there is no mention of young carers as they were designated outside the scope of the guidelines (NICE, 2008: p117). Similarly, while the final version of the guidelines acknowledges the needs of parents who care for young people with Borderline Personality Disorder, there is no mention of the parents with Borderline Personality Disorder who are cared for and live with their children (NICE, 2009). Yet approximately 75 per cent of all diagnoses of borderline personality disorder are assigned to women (Moran, 2003).

Given the paucity and variability of coverage in NICE guidelines, it was clear that there are no standard criteria in the template made available to guideline development groups to assist them when defining the scope of new guidelines to include the impacts of mental health problems on parenting and family welfare, which illustrates the omission in one of the primary sources of guidance for mental health services (SCIE, 2009).

SUMMARY

The negative impact of not including mental health services in the policy, planning, delivery and evaluation of the 'whole family' interventions described above is clear. Adult mental health services are arguably one of the services who have worked hardest to develop strategies to engage some of the most vulnerable groups in society, including those individuals that do not want to receive treatment and support, many of whom are parents. Their invaluable experience of engagement in difficult circumstances, their specialist skills in mental health, their access to resources and existing caseloads of families who could benefit from these family programmes, has not been utilised or prioritised. This has the dual impact of not being able to reach the target population most in need and for those families that do engage there is no clear sign-posting to pre-agreed timely mental health care for parents or children who present to these projects with mental health difficulties. Unfortunately, the omission of mental health services is not surprising, despite the increasing number of legislative and policy injunctions urging services to work together. These include *The mental health social exclusion report*, ODPM, 2004; Health and Social Care Act (DH, 2012); *Working together to safeguard children* (DCSF, 2012); *No health without mental health* (DH, 2011) to improve outcomes for all family members, Every Child Matters (DCSF, 2004) which sets out the national framework for local change programmes to build children's services, and strongly recommends inter-agency collaboration between children's social care, child health and education, but does not include collaboration between adult and children's services.

Whole family approaches to the consequences of social exclusion presents both tensions and opportunities. It cannot be assumed that whole family approaches are appropriate or useful for all families or for all needs. Whole family approaches do not necessarily address the needs of some individuals or ensure that family life is robust and promotes wellbeing. International evidence also reflects the UK experience of large scale preventative programmes struggling to respond effectively to the needs of families experiencing chronic difficulties – however there is as yet limited documented evidence about successful next steps in preventative family provision (Cabinet Office, 2007). Therefore, despite the array of family aware and family-

focused policy interventions implemented over the past 10 years, there is evidence that the inverse care law continues to apply to families affected by parental mental ill-health and social and economic disadvantage (Hart, 2000). Even though such families would have the most need for family support, services with the most potential to help are furthest from reach. Continuing to review the government whole family initiatives is encouraging particularly in regard to reviewing and improving the take up of services by the target populations. The early response for example to the large numbers of families presenting at FIPs with mental health problems has resulted in some of the new FIPs being mental health specific.

The government's intention to deliver new ways of working with individuals and families set out above indicates good intention. It also demonstrates an attempt at achieving coherence, in regard to the inclusion in adult policy of paying attention to the adult as a parent and to their children; in the cross-government programmes of work that incorporate a think family perspective; and in the new whole population approach to promoting good mental health for all family members. However, despite repeated exhortations by government for services to remember to think about individuals *and* families and to work in collaboration with other agencies to achieve the best outcomes, organisations and practitioners are still struggling to achieve the cultural and structural changes needed to implement policy messages into everyday practice. This is not to say there have not been improvements, but rather than there are some issues that are particularly resistant to change; for example, adopting family eligibility thresholds for services and addressing the information technology issues that we are told make it so difficult to share, collect and analyse important information. This highlights the need for greater emphasis on the dissemination, implementation and evaluation of policy developments and this need is further highlighted by the pieces of practice guidance that were reviewed in this chapter.

In regard to the *Think child, think parent, think family* guidance, it seems that without some 'teeth' to support implementation and a longer period of evaluation, the impact and learning from this whole systems approach to improvement will be diminished, as many of the recommendations will remain neither tried or tested. And without extending the period of evaluation it will be impossible to collect any reliable findings about family outcomes. The NICE guidelines, however, are probably amongst the

most referred to and adhered to guidance in mental health services, and therefore not incorporating a think family perspective and criteria into the NICE guideline development template means a very important chance to disseminate and implement government policy in this area is being missed.

The 'too hard to change' policy and practice issues identified here make it possible later in this research to explore whether and how these barriers are overcome or negotiated in the examples of success that parents, children and professionals describe.

THE LOCAL CONTEXT

This section of the chapter is about the local context in which the research takes place. It describes the two research sites, the organisations in each site and their role in the research. The two research sites are the London Borough of Lewisham and Liverpool. Both took part as implementation sites for the *Think child, think parent, think family guidance* (Diggins, 2009) described earlier in this chapter under *Professional guidance*. Whilst this involvement would have raised the profile of parental mental health and child welfare work in these localities; because *both* were involved it was not envisaged that this would result in any significant inconsistencies in the data between the two. To increase the visibility of the researcher in this research process my relationship with the two research sites prior to and in parallel to the research is set out in the final section of this chapter.

<u>Research site 1 — London Borough of Lewisham</u>

The first of the two research sites is the London Borough of Lewisham, which is the second largest of the 14 inner London boroughs. It covers an area of 13.4 square miles with a population of 248,922 residents (ONS Census, 2001). Of this population, over 35 per cent come from black or minority ethnic (BME) communities. This is significantly higher than the London average of 28.8 per cent and considerably higher than the average for England which is 7.9 per cent. Over 30 languages and dialects are spoken. The borough has a younger age structure than the national average with around a quarter of residents aged 19 years or younger.

Deprivation and Poverty in Lewisham

Deprivation is a major factor, with household income being well below the London average. The Department of Environment Transport and the Regions identified four wards in the borough as being in the worst 10 per cent in the country for employment, with 21 wards in the same category for housing; five for education; and four for child poverty.

An above average proportion of the population has low levels of literacy and numeracy. At November 2005, there were 29,280 households in Lewisham in receipt of housing benefit. There is a close link between deprivation and poor health and an increased need for social care services.

Mental Health in Lewisham

There is a close relationship between psychiatric disorder, various measures of poverty and social deprivation. The OPCS *Surveys of psychiatric morbidity* (1995) indicate that the incidence of neurotic disorders in the South East Thames region is higher than the national average and women in the region have the third highest rates nationally. In Lewisham in May 2006, 5,470 adults were claiming Incapacity or Severe Disablement Allowance because of 'mental disorders'. Between April and December 2001, an average of 1,531 patients were registered as standard and 1,136 were registered as enhanced on the Care Programme Approach Register. These levels are significantly higher than the national average.

Refugees and Asylum Seekers in Lewisham

Refugees and asylum seekers may have health problems arising from their recent experiences, such as a higher incidence of stress related mental health problems. It is estimated that there are between 9,000 and 11,000 refugees and asylum seekers in Lewisham. Many health problems are linked to their poverty and deprivation with 80 per cent of asylum-seeking children unable to maintain good health (CPAG, 2004).

Participating organisations in Lewisham

The four participating organisations/services in Lewisham were:

1. Family Action Lewisham Building Bridges Project

2. Family Health Isis
3. Lewisham Community Mental Health Services
4. Lewisham Child and Family Social Care Services

Staff at Family Action Lewisham Building Bridges and Family Health Isis identified potential research participants – parents and children – who met the research criteria and they were invited to take part. The same organisations were available to provide assistance and support to parents and children who took part. Key workers for these parents and children from Lewisham Building Bridges, Family Health Isis, the Community Mental Health team and the Children's Social Care (if they were involved in supporting the family) were also invited for interview. The file records from each organisation were reviewed if service users' consented. A description of each agency follows.

Lewisham Building Bridges

Family Action (formerly the Family Welfare Association) is one of England's leading family charities and it supports over 45,000 families every year with over 100 services in communities across the country. Family Action has been running family support services using the Building Bridges model since 1999, when the first project opened in the London Borough of Lewisham. There are now 14 projects in different locations across England. The model is also used by services supporting parents with learning disabilities and other complex needs. The Building Bridges model was developed to 'bridge' the gap that can exist between adult mental health and children's service by providing a direct flexible and holistic service to meet the needs of families where parents have mental health problems. The key characteristics of the Building Bridges model are set out in Box 1.

BOX 1

KEY CHARACTERISTICS OF THE FAMILY ACTION BUILDING BRIDGES MODEL

1. The service has been designed to meet the needs of families where parents have profound and enduring mental health problems. The model has now also been used for work with a wider group of families affected by parents' complex needs.
2. The starting point is families' perceptions of their needs and the issues they want to address.

BOX 1

KEY CHARACTERISTICS OF THE FAMILY ACTION BUILDING BRIDGES MODEL

3. The service offered is flexible and holistic, and as far as possible, tailored to meet families' needs and circumstances.
4. Led by a qualified person, the service utilises unqualified Family Support Workers.
5. Family Support Workers go into families' homes to help with practical issues as well as providing emotional support.
6. The service is available at times when other services often are not, e.g. weekends, bank holidays, evening, early morning, bath times, bedtimes, getting children to school.
7. The service improves family relationships by enabling parents and children to have a better understanding of each other's needs.
8. The service helps parents to access and co-ordinate their relationships with other agencies and professionals.
9. The service improves communication between the various agencies involved with families.
10. The service is task-centred and time-limited.
11. The service uses internationally validated clinical tools to measure the effects of service intervention.

The Building Bridges project services are available to any family in Lewisham where there is a parent or carer with day-to-day care of dependent children, whose mental health difficulties are seriously impacting on their ability to have a stable family life. Self referrals and professional referrals are accepted. The project adopts a whole family perspective and seeks to address the often competing sets of needs of parents and children, by supporting parents in their parental role and responding to the related, but separate, needs of children. They aim to work closely with health and social care agencies locally to encourage a unified and co-ordinated service.

During the time that this service has been operating in Lewisham, the project has experienced difficulties in maintaining and further developing some aspects of the service they offer, due to the tenuous nature of funding for voluntary sector projects. This is further impacted by the particular funding difficulties that exist for projects that offer services to both adults and children experience. Criteria for funding and funding streams are primarily separated into adults and children's services. Those

services offering help to both parents and children that span the interface between adults and children's funding are hit particularly hard (Diggins, 2009).

The Building Bridges service is positively regarded by community mental health and children's social care services and by many of the parents and young people receiving support, as evidenced in their service monitoring data. This reputation has resulted in this project being seen as an integral part of multi-agency service provision in Lewisham for parents with mental health problems and their families.

Family Health ISIS

Findings from the Commission for Healthcare Audit and Inspection *Count me in census 2007* show that African Caribbean people using mental health services continue to be misdiagnosed, over-medicated, and subject to higher rates of control and restraint than their White counterparts. People from the Black community are also more likely to be placed in seclusion, despite having similar rates of mental ill health as any other ethnic group.

Family Health Isis is a voluntary organisation and registered charity in Lewisham. It was founded in 1986 by a group of mental health professionals, service users and community workers who recognised the need for a service where people from the community could feel safe when accessing information, support and advice on mental health care. It provides a range of community mental health services to African and African-Caribbean people who live and work in the borough. The organisation's head office and day centre are based in Catford, in the centre of the borough, and the Assertive Outreach Team based in Deptford, in the north. The aims of the organisation are set out in Box 2.

BOX 2 FAMILY HEALTH ISIS – AIMS OF THE ORGANISATION

1. To provide a staffed centre aimed specifically at meeting the needs of African and African Caribbean people with mental health problems, currently or in the past, along with their carers, family and friends.
2. To encourage discussion and exploration of mental health issues by the African Caribbean community.
3. To facilitate a positive contribution by the African Caribbean community to mental

BOX 2 FAMILY HEALTH ISIS – AIMS OF THE ORGANISATION
health service planning and delivery. 4. To work collaboratively with statutory and independent agencies to ensure greater choice and flexibility in service provision to the African Caribbean community.

Family Health Isis has shown a commitment to support clients with even the most complex needs, who in many instances have been turned away from other services. Services provided from the central office and day centre include: Individual support, group activities, advocacy, carer and family liaison, advice and lnformation, training and awareness. The Assertive Outreach Team (AOT) provide a community-based service that compliments existing services by offering culturally sensitive services to people with long-term mental health problems. They provide advocacy and support on a wide range of issues; including welfare rights, housing, and welfare benefits, medical and other issues which service users identify as unmanageable. For those service users who need to go into hospital the AOT will facilitate the process and support members whilst they are in-patients.

The organisation has a strong commitment to raising awareness of the issues of importance in the mental health field as they affect African and African-Caribbean people. They provide training, present at conferences, run workshops and seminars and work collaboratively with a number of local colleges to provide practice placements for students undertaking social and community work training. They hold an open day every month to facilitate information exchanges. Family Health Isis works to provoke dialogue and research into the impact of race, and racism in mental health and recognises the importance of African and African Caribbean groups carrying out research themselves and has carried out or taken part in a number of research projects.

Similarly to Building Bridges, this service is established and respected by the statutory agencies who are their main referrers; particularly for the successes they have had with individuals and families that other services have found consistently hard to reach.

Lewisham Community Mental Health Services

At the time the study took place there were three Community Mental Health Teams (CMHTs) in Lewisham that were responsible for delivering assessment and health and social care support (within the Care Programme for Mental Health Framework) to Lewisham residents aged between 18 and 65 with significant and enduring mental health problems. Each of the three CMHTs were made up of a number of smaller multi-disciplinary teams (comprising doctors, psychologists, social workers, community psychiatric nurses, occupational therapists and support staff). These teams were: *Assessment and brief treatment, Home treatment, Recovery and support, Forensic, Assertive outreach* and *Early onset psychosis*. People are seen in outpatient clinics and in their own homes. All of the adults/parents who participated in the research were in contact or had significant previous contact with one of the CMHTs.

Lewisham Child and Family Social Care Services

Child and Family Social Care Services are part of Lewisham's Children and Young People's Directorate and they provide services that protect, care for and support children, young people and their families in Lewisham. The service is delivered via four main borough-wide service delivery teams, which are *Child protection, Children in need*, *Family support* and *Looked after children*. All of the children/young people taking part in the research were in contact or had significant previous contact with one of the children's social care teams.

Research site 2 — Liverpool

The second research site was Liverpool. In 2006 the mid-year population estimate for Liverpool was 436,072 (ONS, 2009). Since the 2001 census there has been a steady increase in the size of Liverpool's BME population from 5.8 per cent to 7.7 per cent of the City total population within 2005. The City has the highest 'mixed' ethnic background concentration of people in England. It has significant Chinese, Irish, African-Caribbean, Somali, Arabic, West African, Indian, Pakistani and Eastern European communities and 81 different languages are spoken (CSIP, 2008). Liverpool is a dispersal city for asylum seekers and is the only area other than London that people can seek asylum (after an in-country application which accounts

for 80 per cent of all claims). It also attracts relatively large numbers of Eastern European migrants.

Deprivation and poverty in Liverpool

Liverpool is ranked as the most deprived district in England, according to the index of multiple deprivation. There are also stark inequalities within the city, with some wards experiencing disproportionately high levels of unemployment, ill health and crime. Liverpool has the highest rate of incapacity benefit claimants for mental health reasons in England with a rate of 58.5 per 1000. Currently more than 16000 people receive this benefit, more than twice the national average. People from BME communities tend to live in the poorest parts of the Liverpool, with more than half (56 per cent) living in the most deprived electoral wards. This is in a city that is fourth most deprived in England based on a multiple-deprivation index that includes health inequality. BME communities are therefore also concentrated in areas with the worst health and highest levels of disability. Some groups experience particular disadvantage within this, including Somali, Chinese and Arabic communities.

Mental health in Liverpool

Liverpool has higher levels of mental illness when compared to the rest of the North West and national averages. Liverpool also has high scores on the Mental Illness Needs Index (MINI, 2000), predicting the population prevalence of psychiatric hospital admission. All former Merseyside PCT areas scored above the national average. North Liverpool scored 2.33 (133 per cent above the national average); Central Liverpool 2.31 (131 per cent above the national average); and South Liverpool scored 1.92 (92 per cent above the national average) (Ubido et al., 2004). Just under a quarter of the people in Liverpool (24 per cent) had significant levels of neurotic symptoms; higher than the rate for Great Britain as a whole (15 per cent). Overall, seven per thousand people in Liverpool were estimated to have a psychotic disorder; not significantly different from the estimated six per thousand for Great Britain as a whole (Singleton et al., 2001). For Black people the rates of neurotic disorders are lower than average rates. However, for psychosis the rates among Black people were three times greater than the White population and there was evidence of over-representation of Black people being sectioned under the Mental Health Act 1983 (Liverpool BRM Network, 2009).

Participating organisations

The two organisations/services taking part in the research in Liverpool were:

1. Liverpool Action with Young Carers – A North West Barnardos project.
2. Mersey Care NHS Trust Community Mental Health Services

Staff at Liverpool Action with Young Carers identified potential research participants – young carers and parents from the same families – who met the research criteria and they were invited to take part in the research. Action with Young Carers staff continued to provide assistance and support to parents and young carers who took part throughout their contact with the research. Key workers for the same families from Action with Young Carers and the relevant Community Mental Health Team were also invited to take part. The file records from the organisations were reviewed if service users consented. A description of each agency follows.

Liverpool Action with Young Carers

Action with Young Carers is a Barnardos North West project set up to support young carers living in Liverpool. Young carers are children and young people under the age of 18 years who provide care to another family member who has a physical illness/disability; including mental ill health, sensory disability or problematic use of drugs or alcohol. The level of care they provide would usually be undertaken by an adult and as a result this has a significant impact on their normal childhood. The aims of the Action with Young Carers service are set out in Box 3.

BOX 3 BARNARDOS - ACTION WITH YOUNG CARERS LIVERPOOL – SERVICE AIMS
The overall aim is to provide a flexible, responsive and culturally sensitive service for young carers and their families in Liverpool by: 1. Ensuring young carers have some opportunity to be free of caring responsibilities 2. Ensuring equality of opportunity for young carers 3. Raising awareness of young carers' issues 4. Providing family based support and advocacy 5. Acting as a co-ordinator of services where appropriate

6. Providing information to young carers and their families
7. Providing social and leisure activities
8. Providing practical and emotional support

The service helps young carers by providing advice and practical and emotional support for the young carer and their parent/carer, including: someone to talk to who will listen; group activities so that young carers can meet others in similar situations; help to communicate information about a parent's illness or disability; and opportunities for fun and a break from caring.

Mersey Care Trust Community Mental Health Service

Mersey Care NHS Trust provides specialist mental health and learning disability services for the people of Liverpool, Sefton, and Kirkby. Mersey Care's purpose is to enable people with learning disabilities and mental health difficulties and their carers to optimise their health, life experience and citizenship. There are five Community Mental Health Teams (CMHTs) based in Liverpool. They work with people with severe and enduring mental health problems, as well as those with less severe illnesses who have not responded to interventions provided in primary care services within the context of the Care Programme Approach for Mental Health (CPA). All five teams work on a needs-led rather than age-led basis, but four primarily work with 'adults' (usually over the age of 16); with the fifth team working with older people. All the CMHTs in Liverpool aim to promote mental health recovery, prevent relapse and encourage social inclusion. The CMHTs consist of a multi-disciplinary team (MDT), of doctors, nurses, support time and recovery (STR) workers, social workers, occupational therapists, family support workers and psychologists. People are seen in outpatient clinics and in their own homes.

RESEARCHER CONTEXT

As the researcher for this study, I brought with me a range of prior knowledge, skills, experience and attitudes that could have been potentially advantageous or disadvantageous to the research process. I had prior established relationships with each of the agencies involved in the research to a greater or lesser degree. Whilst I hoped to utilise my previous experience to the best advantage of the research I also needed to ensure that I regularly reflected on how my previous professional roles

and experience impacted on research decisions and I was able to do this in discussions with my research supervisors. Set out in Box 4 below are the key areas of involvement I have had in parental mental health and child welfare work and details of my relationships with the agencies taking part that had the potential to impact on this work. To maintain transparency these issues will continue to be explored throughout the work.

BOX 4 RESEARCHER CONTEXT	
Experience	Relationship to the research
Social work and CMHT management experience	I was a social worker and Community Mental Health Team Manager in Lewisham for nearly 20 years. Whilst I left this post several years before beginning this research I still have close contacts with the service and as a consequence staff taking part may have knowledge of me as a colleague or manager. This issue is explored in chapter 6: *Methodology in action.*
Research experience	My thesis for my MsC in Social Work – *Partnership or Polarisation – How can Lewisham Social Services help facilitate effective joint agency and intra-agency work with families where the parents* have *mental health problems,* was *undertaken* in Lewisham in 1994.
Training	I am a joint author of the *Crossing Bridges* (Mayes et al., 1998) training materials for parental mental health child work which was piloted in Lewisham in 1998.
Family Action Lewisham Building Bridges Project	Whilst on a secondment from my previous role as a CMHT manager I undertook the needs analysis, wrote the project proposal and initial service plan for this first Building Bridges project. It is unlikely that any of the existing staff in the project will be aware of my involvement in setting up the project because of the significant time lapsed.
The Parental Mental Health and Child Welfare Network	I was the project manager responsible for setting up this professional network in 2004 for the Social Care Institute for Excellence. Membership spanned all regions in England including Liverpool and Lewisham. As part of my role I had contact with senior managers, staff and service users (who were either network members or on the network steering committee)

BOX 4 RESEARCHER CONTEXT	
Experience	Relationship to the research
	from all of the agencies taking part in this research.
Think child, think parent, think family guidance – a guide to parental mental health and child welfare work' (Diggins, 2009).	I am the main author for this guide and I recruited the six implementation sites that put guide recommendations into action - these included Lewisham and Liverpool. My involvement with the implementation sites was minimal after recruitment, however, I am known in this capacity to some of the senior managers and staff in both sites as a result of the recruitment process.

SUMMARY

The policy and practice context in which parental mental health and child welfare work takes place is as complex as are the difficulties that families experience. All of the aspects of the research context that are discussed in this chapter will be revisited in subsequent chapters as the research process unfurls and the various contextual factors interact with the research process.

CHAPTER 3 – A REVIEW OF THE LITERATURE

INTRODUCTION

The literature about parental mental health and child welfare spans several decades. Most studies have been concerned with the potential adverse impacts of parental mental illness on child development, risks to safety and at the extreme end, fatal child abuse (Brandon, 2008, Cleaver et al., 1999, Gopfert, et al., 2004, Tunnard, 2004). In contrast, there has been little research about how parents with mental health difficulties and their children can be supported successfully. I hope that this chapter will offer the beginning of an analysis as to why this is the case.

A wealth of research and policy material can be found about this topic. An illustration of this can be found in the Department of Health (DH) summary report from child protection studies, where there are twice as many references about mental illness as about any other parental problem (Cleaver et al., 1999). Contemporary research refers frequently to a number of early texts (particularly randomised controlled trials and longitudinal studies) about impacts and prevention dating from the late 1970's including Rutter (1996) and Beardslee, et al. (1983, 1998). Policy and guidance documents were reviewed for their relevance to parental mental health and child welfare work and to new ways of working and a summary of the contribution of law, policy and guidance documents can be found in chapter 2 – *The context of the research.*

There are very few studies (and hardly any from the UK) that seek to measure the impact or outcomes of different interventions on parents and children's lives in a robust way. The focus is on process or what happens, rather than outcomes, or what changes. Some examples of those interventions (whilst not all having been evaluated) that are considered as 'good practice' by peer professionals, organisations and service user groups are included later in this chapter. These include a number of the projects that participated in the two research sites for this project.

Significant gaps identified in the review were the paucity of research about fathers (almost all of the research is about mothers); the specific experiences of BME communities; and the experiences of families who are separated (i.e. where the child is living with another family member or in local authority care). The latter example is a particularly significant gap given the cumulative and increased risk for children who are 'looked after' of developing mental health problems in childhood and in adulthood.

PREVALENCE AND DETECTION OF PARENTS WITH MENTAL HEALTH PROBLEMS AND THEIR CHILDREN

The prevalence of mental ill-health in Britain is increasing among children and adults, and a third of parents with common mental disorders have children under 16. In a class of 26 primary school children, this could mean that six or seven children are living with a mother with mental health difficulties (Layard, 2005; Meltzer, et al., 2000). Levels of depression are highest among the mothers of young children, lone parents, and the unemployed. A quarter of the adults in contact with secondary mental health services are parents (Parker et al., 2008). The following diagram on high quality national surveys sets out the prevalence rates of mental health amongst adults and children in Britain, followed by a summary of existing evidence as to what is known specifically about adults with mental health problems who are parents and their children.

The prevalence of mental health problems in Britain

One in four British adults experience at least one diagnosable mental health problem in any one year, and one in six experiences this at any given time (ONS, 2001). Although mental disorders are widespread, serious cases are concentrated among a relatively small proportion of people who experience more than one mental health problem ('co-morbidity') (Maj, 2005). About half of people with common mental health problems are no longer affected after 18 months, but poorer people and those long-term sick and unemployed are more likely to continue to be affected for a longer period (ONS, 2003). Women are more likely to have been treated for a mental health problem than men (29 per cent compared to 17 per cent). This could be because, when asked, women are more likely to report symptoms of common mental health problems and seek help (ONS, 2003).

Depression is more common in women than men. One in four women will require treatment for depression at some time, compared to one in 10 men. The reasons for this are unclear, but are thought to be due to both social and biological factors. It has also been suggested that depression in men may have been under diagnosed because men present to their GP with different symptoms (NICE, 2003). Women are twice as likely to experience anxiety as men. Of people with phobias or obsessive compulsive disorder, about 60 per cent are female (ONS, 2001). Men are more likely than women to have an alcohol or drug problem. Sixty seven per cent of British people consume alcohol at 'hazardous' levels, and 80 per cent of those dependent on alcohol are male. Almost three quarters of people are dependent on cannabis and 69 per cent of those dependent on other illegal drugs are male (ONS, 2001).

In general, rates of mental health problems are thought to be higher in minority ethnic groups than in the White population, but they are less likely to have their mental health problems detected by a GP (NIMHE, 2003).

One in four unemployed people has a common mental health problem (ONS, 2001). The connection between economic deprivation, social exclusion and illness is supported by strong evidence and analysis (Acheson, 1998; Marmot, et al., 2008; Townsend, et al., 1992). The two per cent of families who suffer the combined effect of parental illness, low income, educational attainment and poor housing are among the most vulnerable in society (Cabinet Office, 2007). Mental ill-health is known to be a cause and an effect of disadvantage and inequality (Friedli, 2008; Wilkinson & Marmot, 2003).

<u>The prevalence of mental health problems in children and young people in Britain</u>

Mental illness in children and young people is common. Estimates vary, but research suggests that one in five children (20 per cent) have a mental health problem in any given year, and one in 10 (10 percent) at any one time; the majority of which are either emotional disorders or conduct disorders (ONS, 2005; Green, et al., 2004; MHF, 2005). Rates of mental health problems among children increase as they reach adolescence; with disorders affecting 10.4 per cent of boys aged 5–10,

rising to 12.8 per cent of boys aged 11–15; and 5.9 per cent of girls aged 5–10, rising to 9.65 per cent of girls aged 11–15 (ONS, 2005).

The prevalence of parents with mental health problems and their children

Calculating the number of adults in contact with mental health services who are parents and the number of children in contact with children's services who have parents with a mental health problem is problematic. There are a number of reasons for this, which include: staff not asking about or recording early on which of the adults coming to the attention of mental health services are parents and which of the children in children's services have parents with mental health problems; adults with a mental health problem being reluctant to identify themselves as parents because they fear losing parental responsibility for their children; and children also being reluctant to raise concerns as they fear being separated from their family (Parker, et al., 2008; Stanley & Cox, 2008). Further evidence to support these findings can be found in a practice inquiry carried out by SCIE in 2009. SCIE mapped service responses at key stages in the care pathway for parents and their children who were in contact with adult mental health (AMH), child and adolescent mental health (CAMHS) and children's social care services (CSC) in five practice sites in England (including Lewisham and Liverpool). Every one of the five sites reviewed was unable to provide information about the number of adults in contact with mental health services that were parents; the number of adults detained under the Mental Health Act, 1983 that were parents nor the number of children in children's services that have parents with mental health problems.

To gain a more accurate picture of this population, a systematic review of high quality national surveys was undertaken by Parker, et al., in 2008. This review found that approximately a quarter of children aged 5–16 years have a mother at risk from a common problem such as depression or anxiety; and around a third of adults with these common problems live in couples with children. Both lone mothers and lone fathers are more likely to have mental health problems than parents who live in couples, associated with social deprivation amongst lone parents. The 2000 national survey (Singleton et al., 2001) includes data on the prevalence of parenthood among adults who have a psychotic disorder. It shows that being a parent as part of a couple is much less likely amongst adults with psychotic disorders than in the

general population (17 per cent compared with five per cent) but that being a lone parent is more likely (seven per cent compared with five per cent). However, the overall number of people with psychotic disorder is small, which means that these figures should be interpreted with great caution. Smaller-scale studies show that at least one in four adults in acute psychiatric hospital settings may be parents; probably a lot more. However there is no robust conclusion about the prevalence of parents with mental health problems amongst different minority communities (Parker et al., 2008).

The reviews undertaken by Parker, et al. (2008) were carried out using systematic review methods. The researchers used a 'systematic map' (database) (Bates & Coren, 2006) of literature about parental mental health problems, which used a number of health, social care and psychological research databases. This was supplemented by the research teams own searches to bring the systematic map searches up to date. The systematic nature of the study increases reliability and provides an important contribution to our understanding of this population that was only previously available in a piecemeal way. There is, however, one key finding in the study that I think presents a distorted view of what happens in the practice context; which I believe is similarly mis-interpreted in policy. That is:

> '*Professionals, who work with adults, if left to their own devices, are probably not very good at identifying parents with mental health problems or their children. This seems particularly so among those who work with adults with mental health problems in healthcare settings. By contrast, those used to working with children, whether in mental healthcare or in general children and families services, <u>may be</u> better at picking up and responding to parental mental health problems'*. Parker, et al., (2008, pp.19)

The authors' interpretation of the evidence above assumes that children and family services may be better (than adult services) at identifying and responding to parental mental health problems, when there is research data that suggests otherwise. There are a number of strong examples in the literature that were not identified by the research team demonstrating that children's services staff find it equally difficult to identify and respond appropriately to manifestations of mental illness in parents

(Barbour, et al., 2002; Shepperd, et al., 2001; Woodcock ,2003; SCIE, 2009). The message from research should, then, perhaps be that better identification of parents with mental health problems or their children is *everyone's* business and there is significant room for improvement in *both* adult and children's services.

Summary

The above discussion demonstrates the increasing rates of mental health problems in adults and children in Britain. It also sets out what is known about families where a parent is known to have a mental health problem, although the true extent of this population is likely to be much higher than currently estimated. However, given the number of adults of child bearing and rearing ages with mental illness there are important public health implications for both adult and children's services. The scale of the challenge is increased when the life-span and cross-generational impacts of mental illness and factors associated with mental illness are taken account of which will be discussed in the next part of this chapter.

Screening, detection and recording processes in *both* adult mental health and children's services need to be improved, as without this improvement many individuals and families in need will remain invisible to practitioners and policy makers. Furthermore, given the high and increasing rates of mental health and behavioural problems in children, it is not only imperative that adult and children's workers are able to identify and act on signs of mental ill health in adults who are parents, but also in the *children* they come into contact with. However, whilst effective identification methods and recording systems need to be routine, they also need to be non-stigmatising and avoid false negatives and false positives.

Many of the studies and reviews mentioned in this chapter (Kearney, et al. 2003; SEU, 2004; Tunnard, 2004; Parker, et al., 2008; Stanley et al 2008) highlight the stigma and fear that parents and children have about approaching and receiving public services. Stigma can create barriers and distrust so that some parents prefer not to be identified as having mental health difficulties (Parker, et al., 2008). Similarly, some adults with mental health difficulties are wary of discussing their children in mental health service settings. As a consequence, both children and parents can miss out on being offered appropriate support (Abrahams & Pennington

2008, Mayes et al., 1998). Children need adults to make them 'visible' because of their age and status and their restricted agency and powers, and they usually only access services by an adult 'proxy' acting on their behalf (Webb, 1998). Services provided by the voluntary sector are seen by some parents and young people as 'safer' avenues of support for themselves and their families (Tunnard, 2004; Morris, 2007). These experiences are not new, yet there are very few examples of services pro-actively working together to try to change these perceptions and reassure parents and children that identifying a need for support is a way of avoiding, rather than precipitating, child protection measures.

MENTAL HEALTH AND PARENTING

Parents who find they do need help can be worried about coming forward for help until it is too late and they are in crisis. Women, and particularly Black women, are fearful that their children will end up in local authority care (Parker, 2008; Darton, et al., 1994; Barn, 1990). This fear is not unrealistic. Quinton & Rutter (1984, p.211) found that nearly half the mother of children who had been in care at least twice had been psychiatric in-patients, compared to only one in 50 of a matched control group of mothers whose children had not be in care. Black women are particularly likely to have their children taken into care following a diagnosis of 'mental illness.' Barn, (1990) found 80 per cent of Black mothers with children in care were referred for mental health reasons, as compared to only 20 per cent of White mothers.

Despite the increase in vulnerability to depression when looking after young children at home, the majority of children are not catered for through local authority day nurseries, registered private nurseries or registered child-minders, and what is available may be too costly. Absence of childcare support to enable parents to attend appointments for their mental health, or appointment times that coincide with when children have to be picked up from school, or when they are on holiday from school, are all ways that make services less accessible to parents. Trying to have visits with your children whilst you are in hospital can be a nightmare. There are rarely suitable rooms to meet with children, not enough support from staff to help facilitate the visit and an atmosphere that does not generally welcome or encourage contact (Darton, et al., 1994; Robinson & Scott, 2007). A parent who is hospitalised may worry about who will look after the children whilst they are in hospital; when

their partner will be able to go back to work; how affordable childcare is going to be; whether they will need to leave hospital before their treatment is finished to avoid the children going into local authority care, or their partner losing their job. Hospital admissions may be necessary, but they can also lead to further problems; for example, loss of income or an interruption in welfare benefits can have long-term impacts on the whole family. For parents, it can be difficult to make best use of therapeutic interventions if you are worried about what is happening at home and what you will be returning to.

Troubled lives, a study carried out in the London Borough of Lambeth by Falkov, (1995), looked at the psychiatric morbidity in school-aged children living with a psychotic parent. Thirty five families were involved in the study. The aim of the study was to conduct a systematic enquiry into an 'at risk' group of children's understanding about aspects of parental psychosis. Based on a cognitive-adaptive hypothesis that children's understanding has a protective function in coping with adversity, the key question was whether children who provided more coherent accounts of their experiences with their ill parents (according to interview responses) would demonstrate better adaptation as reflected in measures of psychiatric morbidity, self esteem and perceptions of family relationships than children who provided less coherent accounts. The limitations of this study were the small sample size, the absence of a matched comparison group and uncertainty about the representativeness of ill parents who agreed to participate. Nevertheless the non-specific findings from the study provide useful evidence about opportunities for positively engaging families in discussion about parental illness, despite the stigma associated with the emotive issue of involving children in such discussion.

Findings included:

1. One in two children have significant emotional and behavioural problems at a 'non-crisis' stage in the parents illness

2. Information on child agency involvement in and out of crisis showed that although nearly one third of the children had had some contact with child care agencies. This occurred mainly during crisis, with only four out of 43 children being referred for help at 'non crisis' times. Thus child agency

involvement is extremely low out of crisis; rising somewhat during crisis; but well below levels of psychiatric morbidity reflected in the Rutter scores used.

3. Parental concerns – 50 per cent of mentally ill parents scored in the clinical range. So one in two ill parents have clinically significant stress levels associated with their role as parent.

One parent from the study expressed her fears and hopes for her child in the following way:

> *Parent: 'I don't think I'm strong enough – If I'd known (about the illness) I wouldn't have had her – It was selfish ...because I thought I might be lonely. She's always saying she loves me, but I know I've failed her.' She goes on to describe how: "....because R (child) is bright, she dominates me – my brain is dead – it's not like it used to be – so I ask her to change the hoover bag. If we get a new phone – she does it – you know Dr. – she's like the mum about the house. So that person's going to take control – they're the superior brain, but then I resent it because I'm the elder ....I hope she finds a good man and a happy life – that this business with me won't affect her future*.
> (Falkov, 1995, p.5)

From a cognitive-developmental perspective, younger children gave more concrete explanations about parental symptoms, and their understanding appeared to be based more on knowledge of physical illness. Only the oldest children conveyed any meaningful awareness of genetic links and children of all ages invoked their own behaviour as an important factor contributing to actual or potential parental relapse. This study, despite its limitations, identified that some parents are greatly burdened by their concerns about the children and by their childcare responsibilities.

THE IMPACT OF PARENTAL MENTAL HEALTH ON CHILD MENTAL HEALTH AND DEVELOPMENT

The potential negative effects of parental mental illness on children has been widely studied and reported. This section explores the direct and indirect impacts on children as identified in the literature, including: the range of impacts of child mental

health and development, the experience of young carers, and the lifespan and intergenerational impacts of mental illness. Any aspect of a child's development can be affected when living with a mentally ill parent; including cognition, language and communication, emotional and physical health, behavioural and social development. Existing emotional, behavioural or developmental problems or physical illness can be exacerbated and add to the burden of the mentally ill parent, or new difficulties may emerge (Falkov 1995; Falkov, 1998; Rutter & Quinton, 1984). However, many studies (Beardslee et al., 1983; Rutter & Quinton, 1984; Meltzer et al., 2003; Clements et al., 2008, Cleaver et al., 2012) agree that disorders in children are not tied to specific types of mental disorders in parents.

Children of mothers with poor mental health are five times more likely to have a mental health problem themselves (Meltzer et al., 2003; Clements et al., 2008). They are 3.4 times more likely to have persistent emotions problems, and seven times more likely to have a persistent conduct problem (Clements et al., 2008). Children of depressed parents have a 50 per cent risk of developing depression by the age of 20 (Beardslee, et al., 1989). Reasons for children's vulnerability are not always explained. Roy (1990) suggests that major mood disorders, for example, have a genetic basis, thus making the child susceptible. Beyond that, parental illness may create problems in child rearing. Parental bonding with the children may be loosened: the well parent's attention is also likely to be focused on their partner (with the mental health problem), further contributing to the child's feeling of isolation and rejection. These last two factors have considerable power to create emotional disturbances in children. A certain amount of parental neglect may be unavoidable.

Beardslee et al. (1985) compared 37 children from 20 families with a history of affective disorder in one parent with parents of nine children from five families with no history of the disorder. A significantly high rate of general psychiatric impairment was found in children of parents with a major disorder and a marked amount of major depression, according to the Diagnostic and Statistical Manual (DSM111), compared to the children of parents without a history of mental illness. Similarly, Keller, et al. (1986) established that the more severe and more chronic the depression in parents, the poorer was the adaptive functioning and the higher was the level of psychopathology in their children.

The following situations taken from a study of young carers of schizophrenic parents by Webster (1992) illustrate what some of the children interviewed experienced living with a parent with a mental health problem. They had to go to different relatives away from school and friends (because Mum's in hospital) or to 'play out' (because Mum's 'not well'). The young people interviewed also spoke about the indirect impacts and experiences of parental mental illness including: their role as confidants, their attitudes to their mother's illness, and the 'age' inappropriate responsibilities they have to undertake. Adults in the families avoided listening to children's worries about problems at home, although parents did confide in their children about their own concerns and anxieties. Fathers tended to discuss their irritations with the schizophrenia and the possibility of divorce with their children. Talking about divorce:

> '*My dad nearly got divorced once, and I wouldn't want that. Well, I thought it was hard on my mum because when she came out of hospital she'd have had nowhere to go. But then she was being down and grumpy and a bit violent and so I thought with her like that, she would have been better out of the way. So I was split two'"* Webster (1992, p.326). Anthony, (1976) cited in Webster, (1992, p.327) describes children *'turning off'* their psychotic parents as they recognise their emotional limitations and beginning to mother themselves.

The timing of parental mental health problems can be significant and can exacerbate impact at key times during a child's development. For example, the early years of a child's life are a critical time for building and developing emotional and mental resilience. (Ghate & Hazel, 2002; Hildyard & Wolfe, 2002; Irwin et al., 1984; Murray, 2002; Perry, 2002; Siddiqi & Hertzman, 2007, Cleaver et al., 2012). Other challenges include dealing with the arrival of a sibling at the same time as their mother's first episode of illness, effects on school performance in older children, or examinations or school transfers coinciding with an episode of illness.

Parental mental health is also a factor in the number of children known to children's social care services. Child care social workers estimate that 50–90 per cent of parents on their caseloads have mental health problems, alcohol or substance misuse issues and it is a significant factor for children entering the care system,

(Kearney, et al., 2003). Approaching the incidence from the perspective of children in local authority care, one study found that nearly half the mothers of children who had been in care at least twice had been psychiatric in-patients, as compared to only 1 in 50 of a matched control group of mothers whose children had not been in care (Quinton & Rutter, 1984). Isaac, et al. (1986) concluded from their study of 31 families with children who had stayed in foster care for a minimum of 12 months, and 26 families from the same district with children who had been in foster care for up to three months, that parents of children in foster care for the longer period were more likely to have received psychiatric treatment, and this was correlated with a high rate of past and current psychiatric disorder in the total sample of parents. Parent psychiatric distress was an important factor in influencing children's admission and discharge from foster care.

Young carers

Young carers' research emphasises that young carers' looking after parents with mental health problems will have less obvious but more complicated needs than those whose parents have visible, predictable illnesses or disabilities (Elliott, 1992). Their family circumstances are likely to be different to other young carers; they will be less static with more ups and down leaving them not knowing what is going to happen next because there are so many variables (Cohen, 1994, p.23). Of the 175,000 young carers identified in the 2001 census, 29 per cent – or just over 50,000 – are estimated to care for a family member with mental health problems (Dearden & Becker, 2004), – though it is noted that this is not a reliable estimate of numbers of young carers in the UK because of poor methods of detection and under-reporting (Grant, et al., 2008). Though the Carers Act (2004) emphasises the need to work preventatively with children and young people, young carers of parents/carers who have mental health problems are the group of carers most likely not to be offered a carers' assessment of their needs (Frank, 2002; Dearden & Becker, 2004; Grant, et al., 2008).

Children are often ashamed or embarrassed by their situation, possibly ostracised because of their parents mental health problems, since the stigma associated with mental illness is sometimes projected onto the child. Their school work may suffer, they may often be late or unable to concentrate, worried about Mum or Dad at home.

They do not tell teachers or others about what is happening for fear of the reaction. They might have been told, or realised themselves, that if they ask for help, this might lead to their parent having to go to hospital and or themselves being taking into care. Many have problems leading a 'normal childhood'; going out with friends, asking people home to their house, going places without being scared of what might happen whilst they are away. Maintaining friendships may also be a problem because peers do not understand what 'caring' is like.

Research in Southall (Young Carers, 1992, p.3) found increased difficulties felt by young carers from BME families, where a parent has a mental illness. These included '*guilt, isolation, anger and confusion,'* and the lack of resources – first language literature, interpreting, advocacy, and training – to support families or professionals working with them. Young carer's projects can provide important opportunities for children to talk about what is happening and spend time with other young carers who know what 'caring' is about.

A CONTINUUM OF NEED

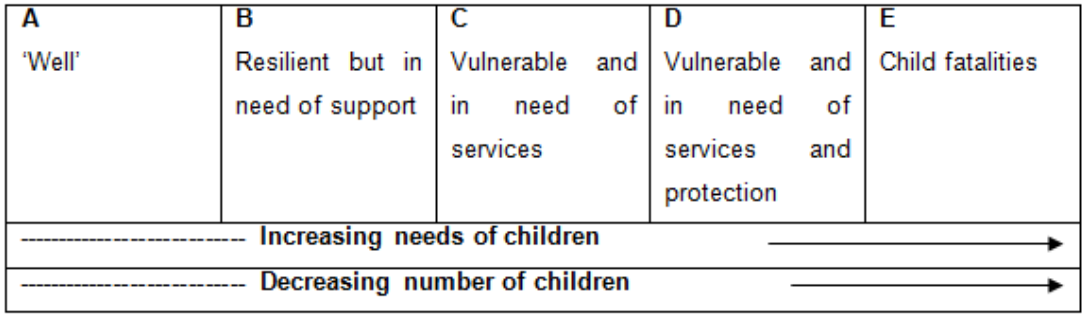
Parental mental illness is only one of a range of inter-related risk factors which may lead to the risk of significant harm to children and young people (Brandon, et al., 2008). There is usually no simple, direct relationship between parental diagnosis and the nature of the child's difficulties. This is because outcomes depend on child characteristics, alterations in family functions, and stressors and protective factors other than parenting; for example, the presence or absence of domestic violence, alcohol and drug misuse, low income, and social isolation. However, serious psychiatric disorder is a factor in approximately 30 per cent of fatal situations of child abuse (Brandon, et al., 2008). Fortunately, this most extreme manifestation of child abuse is a relatively rare occurrence. A narrative review of research about child homicides carried out by Pritchard (2004), found consensus in the research literature that most killings of young children are committed by parents, both mothers and fathers, and that cohort and longitudinal research shows a consistent relationship between diagnosable mental illness and child homicide. Pritchard observes that child homicide and serious injury are statistically so rare that actuarial models to identify and predict harm to an individual child are not possible – invariably they over-predict because of false positives. Nevertheless, certain combinations of factors such as a

previous history of assaultive behaviour, severe depression, psychotic ideas which implicate the child and environmental stressors should set 'all the alarm bells ringing' (Pritchard, 2004).

Falkov, (1995) in his analysis of 100 child death reviews (according to the DOH guidance accompanying the Children Act (1989), found that of the 100 *Section 8 Reviews (*Serious Case Reviews*)* examined, thirty two contained evidence of definite parental psychiatric disorder and/or substantial involvement with psychiatric services. Despite a large number of recommendations in each of the reviews, there was a striking concordance in core conclusions – service provision is fragmented; there is poor inter-agency communication; professionals working with children lack experience in adult mental health and there is insufficient emphasis on child welfare and child protection amongst adult psychiatric services. Recommendations in both adult and child death reviews include improving communication, coordination and collaboration within and between all services and agencies, to better support mentally ill parents who are struggling to meet the needs of their children, including their safety (Woodley Inquiry Team, 1995; Falkov, 1995).

The potential impact of parental mental health on children can be understood as a continuum of need. Not all children will be adversely affected by parental mental illness. The impacts on children of living with a mentally ill parent range from no adverse impact to the extreme of child death. Rutter & Quinton, (1984) found that, over a four-year period, a third of the offspring of consecutive new psychiatric cases exhibited a persistent disorder; a third had transient psychiatric difficulties; and a third showed no emotional or behavioural disturbance. Controls from the same area showed comparable rates of transient disturbance but half the rate of persistent disturbance, such as conduct disorder. This continuum of need is illustrated by Mayes et al. (1998) in Diagram 1 which sets out the range of categories of need that were found amongst children and how as the level of need in the different categories increases (A to E) the number of corresponding children decreases.

Diagram 1 – A range of need amongst children of mentally ill parents



(Mayes et al., 1998)

LIFESPAN AND INTERGENERATIONAL IMPACT OF MENTAL ILLNESS

An individual's mental health and wellbeing is a product of both current and past circumstances and experiences. Research identifies the life-span and inter-generational impacts of mental illness on parenting and the child over time and across generations. Poor mental health in childhood is often the underlying factor behind risk behaviours (including smoking, substance abuse, and risky sexual activity) and health outcomes, (including teenage pregnancy, eating disorders, injuries, bullying and violent behaviour). It is associated with low educational performance and absenteeism and increased offending and anti-social behaviour (DH, 2010). Up to half of life-time mental health problems start before the age of 14 and continue to have a detrimental effect on an individual and their family for many years (Kim-Cohen et al., 2003). A quarter to a half of adult life-time mental illness is preventable through prevention and early intervention of mental health problems and disorders in childhood (Kim-Cohen et al., 2003). This highlights the important public health implication of how not intervening preventively in the present can end up as crisis management later, and over time the creation of another generation of people with mental health problems. See also page 46 for more about early intervention and prevention.

SHIFTING THE BALANCE – RISK TO RESILIENCE

There are many factors that influence (both positively and negatively) the overall impact on children and adults when a parent is mentally ill.

Stigma and discrimination

The stigma associated with mental ill-health causes difficulties and hardship, and contributes to social exclusion and isolation (MHF, 2000). These impacts are felt disproportionately by particular groups and parents are one of four groups least likely to access mental health services and support (ODPM, 2004; Repper & Perkins, 2003). In a number of studies, mothers with mental health difficulties have said that the fear of losing custody of their children or of being judged unfit acts as a barrier to asking for help from services (Aldridge & Becker, 2003; Canvin et al., 2007; Cowling, 1999; Mayberry & Reupert, 2006; Stanley et al., 2003). There is also increasing evidence that people from BME groups experience greater discrimination in accessing preventative mental health services (Sashidharan 2003; SCMH, 2002) and a small body of research also shows that the jeopardy of discrimination is increased even further for those who are parents (Barn, 1990; Greene, et al., 2008).

Resilience

Resilience is broadly understood as positive psychological adaptation in circumstances where difficulties – personal, familial or environmental – are so extreme that we would expect a person's cognitive or functional abilities to be impaired (Rutter, 1985; Garmezy, 1991; Masters & Coatsworth, 1998). Where children make favourable progress in unfavourable circumstances, research has identified three different kinds of resilience:

1. Overcoming the odds -being successful despite exposure to high risk; for example low birth weight babies.
2. Sustaining competence under pressure – adapting to high risk; for example children who develop coping strategies in situations of chronic stress, such as children of drug using or alcoholic parents, or children of parents with mental health problems.
3. Recovering from trauma – adjusting successfully to negative life events, for example loss of close relative or abuse.

   (Gibson, 1998; Fraser, et al., 1999)

Where adversities are continuous and extreme, and not moderated by external factors, then child resilience will be very rare (Cicchetti & Rogosch, 1997; Runyan et al., 1998 cited in Barnardos, p.8). Therefore, whilst a resilience-led perspective may

have much to offer, it is unrealistic and unhelpful to rely exclusively on such a perspective, especially in circumstances of extreme adversity (Fraser et al., 1999).

Factors which can promote resilience

People acquire whatever qualities of resilience they have in two ways – by what they are born with through their genes, and by the effects of subsequent social experience. Vulnerability and protective factors can be either intrinsic to individuals (for example, genetic composition, personality or temperament, intelligence) or external to the individual (for example, socio-economic circumstances, social class, cultural context, education and employment). The surrounding environment and an individual's biological make-up will continually interact and influence each other in aiding or hindering their ability to cope with and adapt to living with parental mental illness. These factors will also influence the pattern of the illness, including severity and duration (Falkov et al 1998; Gilligan, 2001).

The presence of multiple risk factors or stressors

Where parental impairment is present, successful child adaptation is most strongly related to parenting performance, rather than the nature of the illness of disability (Tebes et al., 2001). Risk factors are cumulative – the presence of one increases the likelihood that more will emerge. Individual risk or stress factors, on their own, do not necessarily have a serious effect on an adult's mental health, their parenting capacity, the parent-child relationship, or a child's mental health. It is when environmental (external) and/or personal (intrinsic) factors occur in combination that an impact on child and/or parental mental health is much more likely. For example, when three or more stress factors occur together without the presence of associated complementary resources or protective factors, the likelihood of adverse affects are substantially increased. An example could be the presence of drug or alcohol dependency and domestic violence in addition to mental illness with little or no family or community support.

Risk to resilience

When targeting intervention it may not be possible to easily change some of the adversities which families experience (such as poor housing, poverty, or even the parent's mental illness). However, promoting and supporting protective factors (such

as social support and improving the families understanding of mental about mental illness) may help mitigate negative effects and adversities when a parent is mentally ill. This is particularly true when considering effects on children. For children, all protective strategies operate through one or more of the following processes:

- by altering the child's perceptions of or exposure to risk
- by reducing the chain reaction that takes place when risk factors compound each other and multiply
- by helping the child improve self-esteem and self-efficacy
- by creating opportunities for change.

The factors which can exacerbate or buffer the experiences and circumstances of children and adults using the strategies mentioned above relate to:

- the intrinsic make-up of the individual (personal attributes)
- the immediate circumstances (family) or broader social environment within which the individual lives
- life events experienced by the individual.

(Gilligan, 2001)

In addition, there may be optimum situations or times to target specific interventions to boost resilience; for example, assistance with housing or financial problems, which create stress for a parent, affecting both their mental health and the relationship with their child. Transition points in children's lives can also be either threats or opportunities, depending on the individual and family context at that time. Promoting protective factors such as mutually supportive interpersonal relationships, or the presence of children with 'easy' temperaments, may offset risk/stressful factors. It is only those areas that are amenable to influence through social experience that carers, professionals and educators will be able to help with.

Recent work on resilience in poor households also points to the importance of listening to families without judgement; otherwise interventions intended to help or support may misfire. Listening is a prerequisite to building resilience (Canvin et al., 2009, p18). Marginalised families may themselves be demonstrating significant

strengths which might go under-recognised if services focus only on risk avoidance and parenting responsibility.

Breaking the cycle of impacts through early intervention and prevention

Through understanding the cycle of impacts, important opportunities become apparent for health promotion, early intervention and prevention. Supporting mental health and physical development during the early years has a considerable potential to reduce health inequalities within a generation (WHO, 2008). As 50 per cent of mental health problems start before the age of 14, childhood and early adulthood constitute key times to develop personal resilience and social skills that will benefit mental health across the whole life course (DH, 2010). The following research example describes a prevention model that aims to interrupt the potential inter-generational impact of parental mental illness, by promoting resilience and decreasing stressors in the child and the family, to reduce the risk of the child developing depression themselves.

In *A family-based approach to the prevention of depressive symptoms in children at risk: evidence of parental and child change* Beardslee, et al., (2003) adopted a developmental perspective and intervened with families where parents had mental health problems and where the children in the family were approaching the age of highest risk for the onset of depression (in adolescence). The study utilised a family-focused approach to prevention which sought to reduce risk factors and enhance protective factors by increasing positive interactions between parents and children, and by increasing understanding of the parental mental illness for everyone in the family. Two large scale manual-based preventive intervention programmes were designed to provide information about mood disorders to parents, to equip parents with the skills they need to communicate information to their children, and to open a dialogue with children about the effects of parental depression.

The study enrolled families with relatively healthy children (8–15years) of parents with mood disorder. Ninety-three families (88.5 per cent of initial sample), including 121 children, participated in the study. The families were assigned randomly to either a lecture or a clinical-facilitated intervention. The results show that both of these programs do have long-standing positive effects in how families problem solve

around parental illness. Moreover, changes in parents' perceptions translated directly into changes in children's own understanding of parental illness. Parental behaviour and attitude changes and their connection to child changes in understanding identify an important mediating variable: family change. By increasing children's understanding of parental mood disorder, the interventions were found to promote resilience-related qualities in these children at risk. The results demonstrate a significant reduction in risk factors and increase in protective factors in the families studied over a long time interval of 2 ½ years. The results provide support for a family-based approach to preventive intervention.

The limitations to the study are clearly acknowledged by the authors. The study sample was predominantly white and middle class and the authors acknowledge that further empirical evaluation in effectiveness trials is needed to support the broad use of these intervention programs. In addition for both interventions the assessment process may have contributed to intervention effects. Research on the treatment of depression indicates that the non-specific effects of treatment, that is therapist contact, are associated with positive therapeutic change regardless of the content of the treatment programme (Jaycox, et al., 1994 cited in Beardslee, 2003 p,129) and thus to some extent, assessor contact may have contributed to the overall positive findings for both groups. However despite these limitations, this study suggests that, even when parents have a disorder that distorts cognition, carefully delivered cognitively-based interventions can have long-term effects.

The above highlights how understanding the factors that can promote resilience and how adults and children can make favourable progress in unfavourable circumstances is an important focus for practice intervention.

PROFESSIONAL PRACTICE AND INTER-AGENCY PRACTICE

This part of the chapter begins with what parents and children have said they want from services for themselves and each other. Then the context in which parental mental health and child welfare work takes place is set out, including: what managers and practitioners have to say about this area of practice; the perceived

barriers to improving practice; and examples of practice and service developments that have been developed to overcome these. The national policy context and the local context of the two research sites taking part in this study can be found in the chapter *2 – The context of the research*.

What do parents and children have to say?

The following (Box 5) is a synthesis of findings that appeared in Falkov (1998) taken from four separate and relatively small scale qualitative studies, which took place in different regions in England, about what parents and children have said they want from services for themselves and each other (Hugman et al., 1993; NSPCC, 1997; Aldridge & Becker, 1993; Bilsborrow, 1992). Whilst the sample size was small in each study (see below) there was a strong concordance with the findings from each study.

Box 5

BOX 5 WHAT DO PARENTS AND CHILDREN HAVE TO SAY?	
STUDY	**METHODOLOGY**
'Like bees round the honey pot' social work responses to parents with mental health needs – Hugman et al., 1993.	This study involved 24 adults who all were parents and had experience of mental health problems and using professional services. It examined their experiences of parenting and mental health difficulties in relation to professional responses to these two areas of their lives.
Long term problems ...short term solutions – parents in contact with mental health services, NSPCC 1997.	This study involved individual interviews with 20 parents, 10 children/young people and 19 professionals and a workshop where a further 44 professionals and 12 family members took part. Individuals were asked about their perceptions of the problems experienced with mental health and parenting and agency responses to them.
Children who care – inside the world of young carers – Aldridge & Becker, 1993.	This study involved interviews with professionals from health, education, social services and the voluntary sector and 15 young carers ages ranging 3–18 and 4 adult carers who had cared since childhood who at the time of the study were aged between 22–35.
'*You grow up fast as well...' Young carers on*	A total of 11 young carers aged between 9 and 21 years and 46 professionals were interviewed in this study. The

Merseyside Bilsborrow, S., 1992.	study addressed two principal questions: what knowledge do professionals have of the existence and tasks of young carers: and; what are the experiences of young carers and their perceptions of services which are offered to them?

The findings from the synthesis of these studies are as follows:

For themselves, parents want:

- more understanding and less stigma and discrimination in relation to mental health problems
- support in looking after their children
- practical support and services
- good quality services to meet the needs of their children
- parent support groups
- child-centred provision for children to visit them in hospital
- ongoing support from services beyond periods of crisis
- continuity in key-worker support
- freedom from fear that children will inevitably be removed from them.

For their children, parents want:

- opportunities for children to talk about any fears, confusion and guilt
- opportunities for children to meet adults they can trust, and to participate in activities where they can meet other children
- provision of explanation and discussion about the events and circumstances surrounding the parental mental health problems
- continuity of care and minimal disruption of routines during a crisis (including hospitalisation of parent/carer).

Children and young people want:

- age-appropriate information about the illness and prognosis
- someone to talk to – not necessarily formal counselling
- a chance to make and see friends.

Children and young people taking on a caring role want:

- practical and domestic help recognition of their role in the family
- a contact person in the event of a crisis regarding a parent.

In general, parents and children want appropriate understanding and support based on the different needs of individual family members. This support needs to be sustained over time, but also varying to reflect any change in circumstances.

Context for parental mental health and child welfare work

Working with families in which an adult carer is mentally ill can be a complex and daunting task for professionals, with some families requiring many different professionals to come together to make an assessment and to provide support for whole families as well as individuals. Despite the importance of the interaction between the mental health of the parent; the safety and welfare of the child, and the impact of parenting on adult mental health, services tend to be structured around either the adult with the mental health problem, or around the needs of children (Stanley & Cox, 2008). Adults' and children's services are frequently separated by the organisation within which they are located (e.g. NHS trust versus local authority); the professional background of staff; policy and legislative imperatives; information and recording systems and organisational cultures. Staff consider themselves locked in a culture of separate services, separate performance indicators and separate skills, all geared to either an adult or child specialist area (SCIE, 2009; Tunnard, 2004). Practitioners may also be reluctant to work outside what they see as their professional boundaries (Tunnard, 2004; SCIE, 2008). The separation of adult mental health and children's services along multiple dimensions can make it difficult for professionals to take a holistic view of both *individual* and *family* needs. This can mean that some of the family's needs may be overlooked, even though they are already in contact with services. Opportunities for preventing problems from arising in the future may also be missed (Diggins, 2009; Falkov, 2012).

Kearney et al., (2003) examined the interfaces within and between services for families where a parent has persistent mental health, alcohol or drug problems. Using mixed methods, they had discussions with a wide range of stakeholders to

identify their main concerns about this area of work and their views on the solutions. A postal survey of adult and children's social services (109 out of 172 Social Services departments took part), and a follow-up telephone survey and site visits to specific projects were undertaken. The authors of this study point out that workers in all services have far more in common with their colleagues in other specialist services than they might at first think. Staff working in child care are exposed to mental health and drug and alcohol misuse through many of the families with whom they work. Conversely, mental health, drug and alcohol workers are exposed to child care issues. Wherever the worker is based, they may be in contact with parents who have one or more of these difficulties. The researchers argue that this exposure affords then the opportunity to increase professional repertoires. For this to happen, practitioners and their managers need to recognise the characteristics of good practice and derive knowledge from experience. One social worker thought that he had learnt more from his clients than from any professional expert, but this is not a common view. Much professional knowledge is never recognised or systematically recorded and evaluated (Kearney et al., 2003).

SCIE undertook a review of existing practice (2009) in adult mental, child and adolescent mental health and children's social care services in five multi-agency sites in England. The reviewers in this study were told by managers and practitioners from all five sites that whilst the shift in central policy to include a *think family* focus (see policy section in *Context* chapter) was welcome, without the inclusion of a 'must do' element (for example specific performance indicators), the policy would remain difficult to implement. Certainly involving the regulators and introducing mandatory performance targets and guidance could help. However, there has been, and still is, nothing stopping agencies introducing their own local performance targets and monitoring activity to ensure that new policy and evidenced-based practice guidance is adhered to and locally evaluated. The difficulties and complexity surrounding this area of practice seem too often to be assigned to the 'too hard to change' box and are pulled out periodically; perhaps in response to a serious case review, but then put back again, because the cultural change needed to achieve different outcomes seems insurmountable. So the assertion of many managers and staff is that whilst they understand and appreciate the need for a change in practice culture, achieving this change is proving far harder.

However, this is somewhat undermined by the parallel assertion of many of the same managers and staff that they have worked with people that do manage to overcome the barriers to successful practice and deliver a service that 'works' for families (SCIE, 2009). What is interesting in this scenario is the question – what is it that these professionals do differently that enables them to surmount the barriers that others find too difficult to handle?

In addition to the issues raised above, further examples of what managers and practitioners have had to say about barriers to effective parental mental health and child welfare practice are summarised below. These examples are a synthesis of findings taken from Tunnard, (2004) and Kearney et al. (2003):

- Issues of confidentiality and information sharing continue to hamper inter-agency working for the benefit of families (Tunnard, 2004; Kearney et al., 2003).
- Collaborative working across organisations is often about child protection issues, at the expense of family welfare considerations. Organisational frameworks for collaboration are usually based in child protection work, with few equivalent frameworks for children in need approaches (Tunnard, 2004).
- Administrative divisions, finance systems and separate adult and child care legislation and policy make it difficult to work with families (Tunnard, 2004; Kearney et al., 2003).
- There is great status in being described as a specialist (Tunnard, 2004).
- There is still too little clarity about professionals' tasks and boundaries (Tunnard, 2004; Kearney et al., 2003).
- Working with the whole family is skilled and testing work that many staff are unprepared for (Tunnard, 2004; Kearney et al., 2003).
- There is a loss of professional confidence about working with the family as a group and few opportunities to develop the necessary skills (Tunnard, 2004; Kearney et al., 2003).
- Learning from clients was not often cited as a major source of expertise and knowledge (Kearney et al., 2003).

SOCIAL EXCLUSION

Taken individually, gender, race, mental illness and parenthood each carry the risk of discrimination and oppression. The adversities are greatly magnified when they occur together within individual families (Darton, et al., 1994). Separate service eligibility criteria for adults and children that are set very high work against the identification of the combined and interactive needs of the adult and child, which can be complex. The decision not to intervene, based on existing criteria, can lead to some families falling through the service net. It also makes it extremely difficult to identify and prioritise opportunities for prevention (Diggins, 2009). Professionals and services are exhorted in policy and practice guidance to interact in ways that reflect the interaction of the needs of family members whilst remaining entrenched in old practices and separate services.

Families with complex needs have described the hopelessness they feel when faced with multiple difficulties, such as poverty, chronic unemployment, violence, disability, and immigration where survival is a difficult task. When help is sought, families must convince people that they meet the eligibility criteria for services and present themselves in ways which hide their strengths and resources and which exaggerate their failures, in order to access a service (Rosenfeld et al., 1993). As a result:

> '*Practitioners who begin their profession wanting to help those in need can then during their professional socialization come to perceive these families through the lenses imposed by theoretical models and bureaucratic regulations aimed at preventing the families from taking undue advantage of public services… As a consequence, workers learn to view families as manipulative in their efforts to get help, and resistant to all of their efforts to help them'* (Rosenfeld et al., 1993, p132).

Health and social care practitioners were criticised in the *Mental health and social exclusion report* (SEU, 2004) for their low expectations of what service users could achieve and the negative impact this had on their recovery. Focusing on pathology and not taking account of strengths or what service users themselves prioritise resulted in less attention and priority being given to the types of evidenced-based interventions that are strongly associated with promoting mental health recovery,

including: parenting support; help with housing problems and access to welfare benefits; education and employment support; and help with relationships. Service users particularly valued advice, advocacy and the development of user-led facilities, which runs counter to the prevailing direction of practice in this field which has been defined increasingly by statutory responsibilities and a concern with therapeutic intervention (Hugman & Phillips, 1993; SEU, 2004).

PRACTICE AND SERVICE DEVELOPMENTS

The literature reviewed suggests that the time given to developing or commissioning new initiatives in parental mental health and child welfare work is disproportionate to the time and attention given to disseminating, implementing and evaluating them (Kearney, et al., 2003a; SCIE, 2009, Diggins, 2008). Therefore many initiatives described as examples of 'good practice' in the literature do not have the evidence base to support this. Equally some initiatives may not feature enough because insufficient implementation and lack of evaluation has led to poor outcomes and an unreliable account of whether they work, thus remaining neither tried nor tested. An example is *Crossing bridges – training resources for working with parents with mental health problems and their children* (Mayes, et al., 1998) which was commissioned by the UK Department of Health. On completion, a copy was posted to all local authorities in England. However, there were no further efforts to implement the materials or evaluate whether they made any difference. Two years after in their study Kearney et al., (2003a) found that the majority of their respondents (local authorities) were not familiar with *Crossing bridges*.

In addition to the Sure Start, Family Centres, Family Implementation Projects and Family Nurse Partnerships which are discussed in the *Context* chapter of this thesis, the literature identifies a range of practice, service and training developments that have been set up specifically to promote parental mental health and child welfare work. These include: inter-agency protocols; specialist interface managers or practitioners; family support services; training and professional learning and development networks. An example of each of these follows.

Inter-agency protocols

Inter-agency practice protocols are seen as one component of a systematic approach to improving and maintaining effective working together practices (Morris & Wates, 2007; Kearney, et al., 2003a, Kearney, et al., 2003b). Staff interviewed by SCIE (2009) in their survey of five multi-agency (AMH, CAMHS, CSC) sites in England were asked whether inter-agency protocols were effective in their area. The general response was that service protocols can be useful, but only if they are adopted by all managers and practitioners and become an integrated part of day-to day practice. The experience in all five sites was that they each had protocols, although not all staff interviewed were aware of the protocol, protocols were not routinely referred to in assessment, case records or care plans, and they were not enforced by managers. Parents and children were not involved in local protocol development and there were no examples found of regular reviews or evaluations of the effectiveness of protocols in these sites. The impact of these policies is therefore unknown.

Specialist interface recruitment posts

The recruitment of managers and practitioners employed to improve practice across the service interfaces also received mixed reviews. In general, staff perceived the impact of these posts on improving practice as variable. Whilst these specialist roles can be viewed as a valuable asset, there is the potential to create situations where pockets of good practice exist, with the wider training and development needs of other staff not being sufficiently addressed (Diggins, 2008). Feedback also suggests that the success of these posts is particularly dependent on the level of authority the post holders have in their respective organisations (Kearney et al., 2003; SCIE, 2009).

Specifically commissioned services to support parents with mental health problems and their families

An example of a service commissioned specifically to offer support to parents with mental health problems and their families is the Family Action Building Bridges projects. See page 18 in chapter *2 – The context of the research* for a full description of this service model. There are 14 Building Bridges project in England, one of which participated in this research (Lewisham Building Bridges Project). The

Building Bridges service model was developed to 'bridge' the gap that can exist between adult mental health and children's service by providing a direct flexible and holistic service to meet the needs of families where parents have mental health problems (Diggins, 2000). Family Action commissioned a longitudinal external evaluation of the impact of the Building Bridges model and the first interim report was published by Morris in 2007. The evaluation produced positive feedback from other agencies and from parents themselves. Partner agencies valued the projects for their ability to work with families where there are high levels of needs, their positive working relationships with professionals, and the flexible and practical support provided to families, particularly when there were significant concerns about children's welfare. The conclusion of this first report was that the Building Bridges projects exhibit characteristics which have been associated with successful practice, for example: paying close attention to 'getting', 'keeping' and 'engaging' parents; a strong theory base; more than one method of delivery; and working with both parents and children. The projects also use the practical, flexible and partnership approach which research indicates is valued by parents. Results on impact of interventions were variable, for example data collected using the Index of Family Relationships questionnaire which were administered at the start of working with a family, at the close and at a six-month follow-up, illustrate that there was a statistically significant improvement in the average scores when comparing the start score with the score at the end of contact. However, the improvement in scores between the start of contact and six months after contact ended was not statistically significant. The outcomes evidence clearly indicates the services provided by Building Bridges are wanted by people who use services and their children. The independent evaluation suggests a statistically significant improvement in parents' satisfaction with their family relationships and with their parenting, when assessed six months after the period of intervention but further work is recommended to assess longer term impacts.

Inter-agency professional development networks

In 2004, SCIE, in collaboration with partner agencies, launched the Parental Mental Health and Child Welfare Network. Membership spans health and social care and adult and children's services. There are representatives from all regions in England, other countries in Europe and from as far afield as Australia. The network aims to promote joint working between health and social care staff in adult and children's

services. Membership is free and members can access up to date research, policy and practice information about parental mental health and child welfare work. They can contact each other to discuss practice dilemmas and share examples of good practice. The network hosts a number of study days each year to debate topics that are prioritised by the membership. The network is led by a steering group of representatives from leading mental health, family, children's and carers' organisations and networks as well as service users who are parents and young carers. This network is now facilitated by the Social Perspectives Network (www.pmhcwn.org.uk) and is sponsored by the Department for Children Schools and Families (DCSF).

In the early days of the SCIE Parental Mental Health and Child Welfare Network, the priority was raising awareness of the issues that parents and their children faced in accessing acceptable and effective services. Very quickly, however, the top priority for the membership was a plea for overarching guidance for policy and practice that considered the needs and wishes of parents, children and families and enabled staff to make the cultural and practice shift necessary to improve outcomes. Based on the network's priorities, SCIE made contact with the Social Exclusion Unit, which agreed to include a recommendation in its publication Mental Health and Social Exclusion Report (ODPM, 2004) for SCIE to undertake a systematic review of evidence and existing practice and to publish new guidelines for health and social care staff in mental health and children and family services. More details about the review and subsequent guidance *Think child, think parent, think family – a guide for parental mental health and child welfare* (2009) can be found in the *Context* chapter.

In Australia, the national Children of Parents with a Mental Illness (COPMI) initiative developed to promote better outcomes for children of parents with a mental illness was announced in 2001, with the following objectives:

1. Development and uptake of good practice principles and guidelines for services and people working with children of parents with a mental illness around Australia
2. Availability to children of parents with a mental illness and their families, and to people working with them of appropriate resource materials in line with the good practice principles and guidelines

3. Provision of high quality information to the Commonwealth Department of Health and Ageing to enhance future policy development regarding children of parents with a mental illness and their family.

Amongst the resource development of this project has been the development of the www.copmi.net.au web site which was developed for and pilot-tested with a range of people working with families and children affected by parental mental illness. The site includes materials for parents, young people and carers, providing clear links to more appropriate websites for young people and parents, whilst also highlighting aspects of the site which are of most relevant to them. Parents with mental illness and their family members can provide on-line tips for others going through similar situations, and an on-line 'capacity building stories' section allows workers to share information about activities designed to promote the health and wellbeing of 'COPMI' and their families.

Anecdotally, these networks appear to have been very successful in raising awareness and alerting professionals and family members about new research and practice developments and facilitating debate and discussion between families, practitioners, commissioners, educators and policy makers. The network websites are highly populated and are considered examples of good practice in their respective countries. At the time of writing there has been no formal evaluation of their impact on practice or on families.

SUMMARY/CONCLUSION

Research has established the potential direct and indirect impacts of mental illness on parenting; the parent child relationship; and the child, and the extent to which this poses a public health challenge, particularly in the existing context for delivering services to adults and children which is characterized by financial crisis in the UK, cuts and reductions in services, and the stigma and isolation associated with having a mental health problem and being a family who needs to access support from services. The separation of adult and children's policy and health and social care services has created a number of real and perceived barriers to the identification of difficulties for parents and their children and in regarding to working together to

support families despite repeated policy and research recommendations urging practitioners to do so. Awareness about the issues that families face trying to get accessible, acceptable and effective support has risen in the professional population. However, despite the commitment to try to address these difficulties evidenced by the large and increasing numbers of practice development initiatives specific to area of practice, change has been patchy and slow. In contrast, there has been little research about how parents with mental health difficulties and their children can be supported successfully. 'What works' or what constitutes 'success' from the perspective of parents with mental health problems and their children is missing from the literature.

This study aims to begin to address this gap by providing an original contribution to conceptualising and evaluating success in parental mental health and child welfare work.

CHAPTER 4 - CONCEPTUALISING AND EVALUATING SUCCESS

INTRODUCTION

This chapter looks at the potential of the Strengths Model of practice, the New Recovery Model of Mental Health, Self-Efficacy and Mental Health Promotion for conceptual development in this study.

THEORETICAL APPROACHES IN MENTAL HEALTH

The World Health Organisation (WHO) constitution states: '*Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity*.' While the dominant theoretical approaches in mental health have overwhelmingly focused on the individual in isolation – and how their personal 'pathology' may best be understood in medical or psychological terms – a range of alternative frameworks exist which locate mental health difficulties within a wider social context in which family relationships are assumed to play a crucial role. These theoretical frameworks can be useful in exploring both how social (and family) factors may contribute to people's mental health difficulties and how these difficulties may impact on their family relationships and social networks. Resources which strengthen families within communities can also be explored using different theoretical frameworks, including Social Capital, mental health promotion and Family Resilience. Such approaches can arguably challenge the pathologising of either families or individuals (for example, as might occur through a clinical or risk-avoidance focused lens).

In public health, commentators have called for social as well as individual solutions to tackling mental ill-health. Although mental health services have received considerable policy attention since the advent of the National Service Framework for Mental Health in 1999 (DH 1999, DH 2002, DH 2003, DH 2008c, NIMHE 2005), a recent World Health Organisation (WHO) report warns against over-stating the capacity of psychological treatment interventions to ameliorate rising levels of mental ill-health, and asserts that mental distress needs to be understood as a response to inequalities and relative deprivation (Friedli 2009). This type of analysis draws from

a range of psychological and social research and results in a classification of resilience and stress factors as characteristics of communities as well as individuals (Aked, et.al., 2008; Foresight, 2008; Bartley 2006). These commentators agree that multi-faceted and multi-level interventions, which stimulate resilience as well as address mental ill-health, are needed to improve outcomes for families affected by parental mental health and multiple disadvantages. For children, this includes the provision of a range of experiences such as secure attachment relationships, the promotion of self-esteem, self-efficacy and a sense of control, encouragement of pro-social behaviour and stimulating the child's 'theory of mind' (Daniel & Wassell, 2002). For parents, this includes relief from poverty, access to essential services, support with childcare and employment, and maintenance of social networks.

There are a number of theoretical and conceptual frameworks that offer a useful contribution to understanding and evaluating parental mental health and child welfare work. For example in *Young carers work* (Dearden, 2004) the development of a whole family approach has sought to provide a focus on inter-related needs within the whole family, and recognition that both young carers and ill or disabled parents have needs and rights. Within this framework, appropriate service responses may be to meet parents' needs alone, or those of the young carer, or both. This approach recognises that growing up with a mentally ill parent can have a negative influence on the quality of that person's adjustment in adulthood, including their transition to parenthood, but there can also be positive effects. Rather than a chore, caring can be part of a loving parent/child relationship, and an important and valued contribution to family life (Dearden et al., 2004).

The main contributory frameworks used to conceptualise and evaluate 'success' in parental mental health and child welfare work in this study are the: Strengths Model; Recovery Model; self-efficacy and mental health promotion. A summary of each of these frameworks and their applicability to this study are set out below.

THE STRENGTHS MODEL OF CASE MANAGEMENT

In 1992, Saleeby (a social worker) edited a collection of contributions related to an ecological model of mental health, drawn from the biological sciences that emphasised the need for a healthy environment for organisms to develop well. The

collection includes a chapter by Rapp on the relevance of the strengths approach to the field of mental health. The model was further developed and became known as the Kansas, or Strengths Model (Rapp, 1998). The model proposes that mental health workers take a conceptual lead to stop assessing for and identifying problems, deficits, sickness or being unwell and instead help create environments for people with severe and persistent mental illness that are overtly enabling. Rapp & Goscha, (2006) claim that the strengths model challenges the dominant paradigm in mental health services where undertaking an adequate assessment and diagnosis of the 'problem' remains at the core of modern practice. They argue that the traditional approach has been found wanting and the lives of people with mental health problems continue to be marked by poverty, loneliness, limited opportunities for achievement, discrimination, and oppression. The purpose of case management in the strengths model is to assist the individual to identify, secure and sustain the range of resources – both environmental and personal – needed to live, play and work in a normally interdependent way in the community. It is tailored to the individual and the unique needs of each person and helps people to achieve the goals they set for themselves (Rapp & Goscha, 2006).

The six principles of the strengths model are: the focus is on individual strengths rather than pathology; the case manager-client relationship is primary and essential; interventions are based on client self-determination; the community is viewed as an oasis of resources, not as an obstacle; aggressive outreach is the preferred mode of intervention (and) people suffering from severe mental illness can continue to learn, grow and change (Rapp & Goscha, 2006).

The methods can be best organised into five functions:

1. Engagement and relationship: The initial meetings with a person, where the purpose is to begin the development of a collaborative helping partnership.
2. Strengths assessment: The process of gathering information on personal and environmental strengths as a basis for work together.
3. Personal planning: The creation of a mutual agenda for work between the person and the care manager with the strengths assessment as the primary source of information and guidance.

4. Resource acquisition: To acquire the environmental resources desired by people to achieve their goals. To be successful, case managers require ne*w* perspectives concerning 'community' and a wide variety of interpersonal and strategic skills.
5. Collective continuous collaboration and graduated disengagement.

To embrace the strengths perspective requires that all key phases of practice, from engagement and assessment to the evaluation of outcome, look different when the strengths perspective is employed. (Rapp & Goscha, 2006, p.71).

<u>The evidence base for the Strengths Model of practice</u>

This model has been empirically tested and although there are some limitations of the research, due to the small number of studies (nine) and small sample sizes in three of the experimental studies, results indicate that the model is an effective approach (Rapp & Goscha, 2006).

The Strengths Model and the Recovery Model (below) are two approaches in mental health that focus on helping people, not as patients or clients, but as individuals. The Strengths Model is predominantly used in the USA and is not common practice in the UK. Since the Strengths Model was first published in the late 1990's, recovery from mental health problems has become the vision for mental health services, including in the UK.

> '*For the Strengths Model case manager, recovery is the vision to be held for each of the people we serve. The lack of such a vision leads to case management practice that is preoccupied with maintenance rather than growth and achievement. Without the hopeful vision of recovery, practice becomes reactive rather than purposeful and proactive. The recovery vision means that every contact with a person can be an opportunity for building hope, increasing confidence, and taking steps to create a better life. The recovery vision becomes the engine of our strengths-based practice*.' (Rapp & Goscha, 2006, p.33).

MENTAL HEALTH RECOVERY

Roberts and Wolfson (2006) date the origins of recovery-oriented practice to the Tuke family who established 'the retreat in York' at the turn of the 18th century. William Tuke, a Quaker and a lay reformer, set out to create a family-like healing and spiritual environment for members of the Society of Friends. The Tukes showed that moral or psychological forms of treatment in a work-oriented, peaceful and pleasant environment could replace physical restraint. The new meaning to the concept of recovery is seen as a result of the developing 'consumer' movement in the United States, New Zealand and other countries, such as Sweden, in the late 1970's and early 1980's, and in the 1990's in the UK. The new meaning focuses on the ability to lead a better life with serious mental illness and beyond it, even if symptoms remain.

Definitions of Mental Health Recovery

Recovery has generated three principle usages in its application to mental health care. Firstly it can be considered as a spontaneous and natural event, someone who meets diagnostic criteria but overcomes their problems without intervention. Secondly, recovery is the intended consequence of the skilful use of the full range of effective treatments. Thirdly, the experience of personal recovery can occur in the context of continuing symptoms or disabilities. The first usage relates to resilience and robustness and is relatively poorly understood; the second is the focus of evidence-based practice and treatment guidelines; and the third is about the new meaning of recovery in terms of re-kindling hope and ambition for living full and purposeful lives whatever the circumstances (Ralph and Corrigan, 2005). These different concepts are not mutually exclusive, they are complementary and synergistic. Adopting a Recovery approach harnesses the value of current treatments but is directed at living with and beyond the likely continuing limitations of having a mental illness. An emphasis on personal recovery focuses on collaboration, partnership working and self-directed care, all of which lead to choice and control for people who use services, their families and other supporters. The non-dictionary, meaning of recovery has been introduced by people who have recovered from mental health experiences. At its simplest recovery can be defined as*' 'a subjective experience of having regained control over one's life*.' (Knight, 2000). Personal definitions of recovery include the following:

> '*Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again....The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution*" (Deegan, 1988, p.15).

Recovery is also referred to as a process, outlook, vision, and conceptual framework or guiding principle. It is also a UK practice and policy and is fundamental to mental health service delivery.

There is, therefore, no single definition of the concept of recovery for people with mental health problems, but the key idea is one of hope that it is possible for meaningful life to be restored, despite serious mental illness. It is a concept that has attracted considerable enthusiasm and hope in an area often characterised by disillusionment and defeat.

<u>Implications of the Mental Health Recovery Model for practice</u>

Common themes in Recovery include the pursuit of health and wellness; a shift of emphasis from pathology and morbidity to health and strengths; hope and belief in positive change; meaning and spiritual purpose of distress; service supports reconceived as mentoring not supervisory; identity explored as a cultural issue; social inclusion (housing, work, education, leisure); empowerment through information, role-change, self-care; awareness of positive language-use in framing the experience of illness; personal wisdom encouraged in professional practice; and creative risk taking replacing overcautious risk assessment (SCIE, 2007). Professionals in the mental health sector often refer to the Recovery Model to describe this way of thinking.

Research has shown that for the majority of people, relationships with professionals and mental health service delivery is key to Recovery. Putting Recovery into action means focusing care on supporting recovery and building the resilience of people

with mental health problems, not just on managing their symptoms. The Recovery process:

- provides a holistic view of mental illness that focuses on the person, not just their symptoms
- believes recovery from severe mental illness is possible
- is a journey rather than a destination
- does not necessarily mean getting back to where you were before
- happens in 'fits and starts' and, like life, has many ups and downs
- calls for optimism and commitment from all concerned
- Ii profoundly influenced by people's expectations and attitudes
- requires a well-organised system of support from family, friends or professionals
- requires services to embrace new and innovative ways of working.

(*Mental Health Foundation*, 2007).

The evidence base for Mental Health Recovery

Recovery as we know it today is underpinned by two main sources of evidence. The first comes out of longitudinal research on people with the lived experience of schizophrenia (Ciompi & Muller, 1976; Desisto et al., 1995) with more recent examples of high quality studies coming from the literature on employment and recovery (Burns, 2007; Schneider, 2005). These studies have demonstrated the ability of people with long-term mental illness (primarily schizophrenia) to lead an ordinary life in the community even after years of being hospitalised, and for an increasing number to enter competitive employment. The second comes from individualised approaches to recovery with the evidence here coming from the analysis of individual narratives (Copeland, 1992). Pioneers like Judy Chamberlin, who experienced mental health problems and treatment herself, began to record their experiences and tell their stories (Chamberlin, 1978). These narratives have grown considerably since the 1980s and there is now a significant literature of writing by people with recovery experiences (Lovejoy, 1984; Chamberlin, 1988; Deegan, 1988; Leete, 1989; Unzicker, 1989; Coleman, 1999). The accumulated wisdom and witness from such personal accounts in many ways form the foundation of the Recovery approach (Leibrich, 1999; Ridgeway, 2000). These personal accounts,

alongside systematic analysis, have been important contributions to the literature on Recovery. They highlight putting values into practice, being strongly influenced by what is personally meaningful, and being oriented around outcomes rather than inputs (SCIE, 2007).

Putting Mental Health Recovery into action – WRAP Training and Support

To support Recovery there are a number of self-management information resources and tools now available in the UK, including: Wellness Recovery Action Planning (Copeland, 1992), the Manic Depression Fellowship Self-Management Training Programme and self-management books and resources for people who hear voices and self harm (e.g. *Working with voices* and *Working with self-harm*, Handsell Publishing). Perhaps the fastest growing individual approach to Mental Health Recovery is the self-management framework developed by Mary Ellen Copeland in Vermont, USA (www.mentalhealthrecovery.com). The Wellness Recovery Action Plan (WRAP) is a self-help system based on increasing awareness, improving self-care and strengthening supports. In 1989 Copeland began her narrative studies about how people help themselves, get well, and stay well, and in 1992 she published the *Depression workbook'* which is now regarded as a key text in Recovery. Copeland developed the WRAP tool with other people who had experienced serious mental health problems in the United States. They found that a self management plan could be effective in avoiding or moderating the negative effects of their mental health problems. The focus of Copeland's work has been on shifting the system of mental health care toward prevention and recovery through education, training, and research. WRAP aims to shift the focus in mental health care from 'symptom control' to prevention and recovery.

WRAP evidence base

There is an evidence base for WRAP due, in part, to the availability and widespread use of a pre-test/post-test instrument developed by the model's creator and widely used by its facilitators. A number of non-controlled, well-designed quasi-experimental studies (Harding, et al., 1987; Buffington, 2003) have found that the intervention leads to behavioural or attitudinal change, but further research is needed to explore the efficacy and effectiveness of this model in promoting recovery.

Measuring Mental Health Recovery

Work has been done in the United States and in the UK to develop measures of recovery that respond to personal perspectives and lived experience. One measure that is emerging as particularly relevant is the Developing Recovery-Enhancing Environments Measure (DREEM). DREEM is an outcome measure and research tool that is used to measure how 'recovery-oriented' a service is. It is a self-report instrument that gathers information about mental health recovery from people who receive mental health services (Mental Health Foundation, 2007). The National Institute for Mental Health in England (NIMHE) identified DREEM as the most promising of an emerging group of recovery-sensitive measures (Campbell-Orde et al., 2005). However, measures for recovery are still being sought and there is a need for outcome measures in addition to the subjective description by the person in recovery.

Implications of the Mental Health Recovery Model for this study

The significance of Recovery to the concept of success in this study is that Recovery indicates the scope and possibilities of learning from success. The research on parental mental illness is dominated by impact research about what can go wrong, with far fewer examples about *what works* for individuals and families. The absence of accounts of the lived experiences of parents and their children in the parental mental health literature is very significant. This means there is no body of examples about 'what works' or what constitutes 'success' from the perception of parents, children and practitioners that can be evaluated alongside the existing systematic and longitudinal studies on impacts and interventions. The author proposes that this results in decreased opportunities for translating values into practice and in making the shift to outcomes-orientated practice.

SELF-EFFICACY

Virtually all people can identify goals they want to accomplish, things they would like to change, and things they would like to achieve. However, most people also realise that putting these plans into action is not quite so simple. Bandura and others have found that an individual's self-efficacy plays a major role in how goals, tasks, and challenges are approached and ultimately this will increase or decrease their chances of success. The concept of self-efficacy lies at the centre of psychologist

Albert Bandura's social cognitive theory (Bandura, 1992). Self-efficacy is '*the belief in one's capabilities to organise and execute the courses of action required to manage prospective situations'* (Bandura, 1995, p.2). In other words, self-efficacy is a person's belief in his or her ability to succeed in a particular situation. Bandura described these beliefs as determinants of how people think, behave, and feel (Bandura, 1994). Self-efficacy can have an impact on everything from psychological states to behaviour to motivation.

Self-efficacy as a concept is extremely important to this study because of the focus on learning from success. The literature about parental mental health and child welfare is strewn with examples of the potential negative impacts of mental health and the barriers in practice to implementing socially inclusive services. The literature also highlights the negative contribution that low professional expectations of what parents and young people can achieve has on their pursuit of success, for example pursuing opportunities for employment (SEU, 2004). Whilst self-efficacy beliefs begin to form in early childhood as children deal with a wide variety of experiences, tasks, and situations, the growth of self-efficacy does not end during youth, but continues to evolve throughout life as people acquire new skills, experiences, and understanding (Bandura, 1992). This highlights important opportunities for practice intervention that is focused not on pathology and treatment but on encouraging and supporting individuals to believe in themselves and the abilities to live well with mental illness and beyond. The four major sources of self-efficacy are:

1. *Mastery experiences.* The most effective way of developing a strong sense of efficacy is through mastery experiences, (Bandura, 1994). Performing a task successfully strengthens our sense of self-efficacy. However, failing to adequately deal with a task or challenge can undermine and weaken self-efficacy.

2. *Social modelling.* Witnessing other people successfully completing a task is another important source of self-efficacy. Seeing people similar to oneself succeed through sustained effort raises observers' beliefs that they too possess the capabilities to master comparable activities to succeed (Bandura, 1994).

3. *Social persuasion.* Bandura also asserted that people could be persuaded to believe that they have the skills and capabilities to succeed. Getting verbal encouragement from others helps people overcome self-doubt and instead focus on giving their best effort to the task at hand.

4. *Psychological responses.* Our own responses and emotional reactions to situations also play an important role in self-efficacy. Moods, emotional states, physical reactions, and stress levels can all impact how a person feels about their personal abilities in a particular situation. By learning how to minimise stress and elevate mood when facing difficult or challenging tasks, people can improve their sense of self-efficacy (Bandura, 1994).

Implications of the concept of self-efficacy for this study

The concept of self-efficacy as it applies to parents, young people and practitioners, and its association with successful outcomes and learning from success, is central to this study. Practitioners can support parents and children to develop their belief in themselves, by drawing on the sources of building self-efficacy described above. However, the literature suggests that in order to support people and increase their self-efficacy and resilience, practitioners have to first believe that recovery is possible and be 'persuaded' that they (practitioners) have the skills and capabilities to help others achieve and succeed by moving away from the familiar treatment and maintenance model of practice.

MENTAL HEALTH PROMOTION

Public health is a social and political concept, aimed at improving health, prolonging life and improving the quality of life among whole populations through health promotion, disease prevention and other forms of health intervention. Mental health promotion is both any action to enhance the mental wellbeing of individuals, families, organisations and communities, and a set of principles which recognise that how people (adults and children) feel is not an abstract and elusive concept, but a significant influence on health (Friedli 2000)**.** Mental health promotion links to psycho-social wellbeing, and to the wider concepts of social inclusion, inequality,

discrimination and its prevention, citizenship and social capital. Mental health promotion is essentially concerned with:

1. How individuals, families, organisations and communities think and feel
2. The factors which influence how we think and feel, individually and collectively
3. The impact that this has on overall health and wellbeing.
   (Friedli, 2000).

Mental health promotion works at three levels, with each level relevant to the whole population, individuals at risk, vulnerable groups and people with mental health problems:

1. *Strengthening individuals* – by increasing emotional resilience through interventions designed to promote self-esteem, life and coping skills, e.g. communicating, negotiating, relationship and parenting skills.

2. *Strengthening communities* – by increasing social support, social inclusion and participation; improving community safety; neighbourhood environments; promoting childcare and self-help networks; developing health and social services which support mental health; promoting mental health within schools and workplaces, e.g. through anti-bullying strategies and mental health strategies.

3. *Reducing structural barriers to mental health* – through initiatives to reduce discrimination and inequalities and to promote access to education, meaningful employment, housing, services and support for those who are vulnerable.

(Department of Health, 2001)

Effective mental health promotion depends on harnessing expertise, resources and partnerships across all sectors and disciplines. It is interested in processes as well as outcomes and in how participants feel about the interventions that they receive. It adopts the psycho-social definition of mental health as mental wellbeing, rather than the medically-orientated definition of mental health as the absence of mental illness or disease (Tudor, 1996). It acknowledges that how people feel about an

intervention may be just as significant as clinical indicators of impact and that the former will also influence the latter. There are many different definitions of mental health and well-being. These are influenced by individual experiences and expectations, as well as by medical, cultural and religious beliefs (Department of Health, 2001; Bhui & Rudell, 2002; Bhui and Bhugra, 2002). How mental health is defined is of crucial importance to debates about evidence, because it will determine the measures of effectiveness used to assess the success of interventions, for example improvements in self-esteem or a reduction in symptoms of depression.

Evidence base and evaluative framework

The World Health Organisation, (2004) report on its 'systematic review of mental health promotion interventions' stated:

> '*There is a wide range of evidence-based preventive programmes and policies available for implementation. These have been found to reduce risk factors, strengthen protective factors and decrease psychiatric symptoms and disability and the onset of some mental disorders. They also improve positive mental health, contribute to better physical health and generate social and economic benefits. These multi-outcome interventions illustrate that prevention can be cost-effective. Research is beginning to show significant long-term outcomes*.'

Implications of the concept and theory of mental health promotion for this study

The dynamic and contested nature of social exclusion means that social policies and social care practices may not capture or reflect the realities and needs of families. The complexity of family roles, functions, and compositions need to be examined and understood within the modern context. Mental health promotion, like the Recovery Model, is based on the belief in people's abilities and in the possibility of prevention and improvement.

This study draws on the principles of mental health promotion as it allows the research to be viewed through a recognised theoretical framework that acknowledges the impacts of inequalities and social exclusion. It takes both a micro and macro approach to mental health and wellbeing for individuals and communities by increasing emotional resilience, reducing stressors and structural barriers to

mental health. It encapsulates the risk factors and protective factors pertinent to this area of study and it does not rely on the absence of mental illness as the sole indicator of positive mental health but allows for individuals (adults and children) to identify what has been helpful for them and in what context. Drawing on this model, at the same time as utilising aspects of realist evaluation as part of the research design for this study, will allow the focus to be on identifying the components of success: i.e. identifying what an intervention actually does to change thoughts, feelings or behaviours and in what context (Pawson & Tilley, 1997)..

Summary

Mental Health Promotion and the Recovery Model of mental health (in particular) in this study, means not looking through a traditional 'illness' or 'medical model' lens of 'what is the problem and how can we treat it?', but rather, considering how the mental health and wellbeing of parents and their children can be promoted to enable them to live well with parental mental illness and live beyond the illness. Mental health promotion, like the Recovery Model, provides not only an established theoretical and conceptual framework that can be utilised to view and evaluate success (Pawson et al, 1997) but, crucially, it has the additional advantage of providing an alternative recognisable framework for interpreting research findings into messages relevant for professionals in both health and social care and adult and children's services.

CHAPTER 5 - METHODOLOGY CHAPTER

INTRODUCTION

This chapter sets out the philosophical and theoretical assumptions underpinning the research and the research design. The theoretical background to, and the rational for, the methods of data analysis, the research site, sampling strategy and ethical considerations are described to enable the reader to gain a clear understanding of the sequence of events and processes.

Summary of the research design

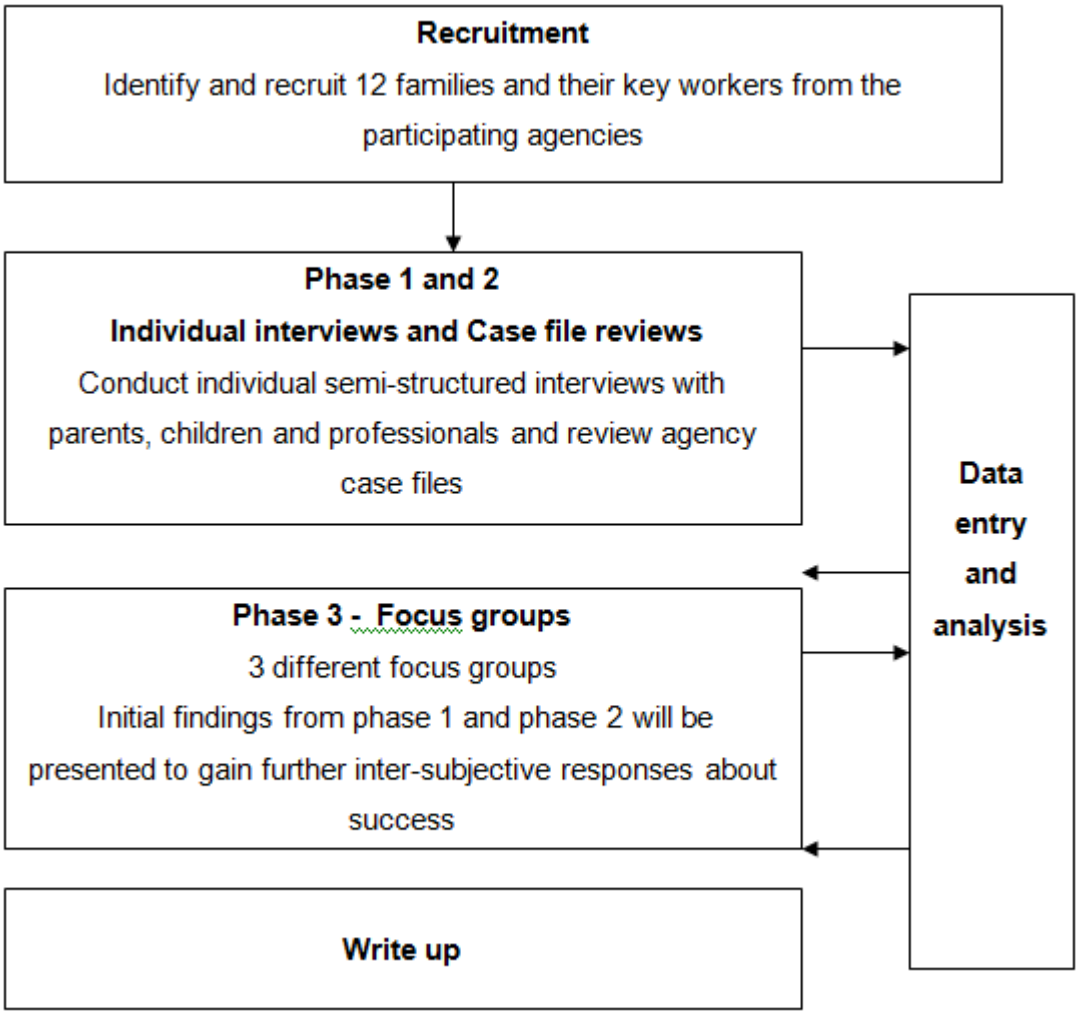
This is a *qualitative* research study using an *interpretative approach.* Within that, paradigm data was obtained to explore these issues, using a *Multiple embedded case study* framework (Yin, 2003), drawing on aspects of *Realist evaluation* (Pawson & Tilley, 2007) with 12 cases. Each case had a combination (not necessarily the same) of a parent, their child of nine years or older and their key workers (from Community Mental Health (CMHT), Children's Social Care (CSC) and the voluntary sector agencies taking part). Parents, children and professionals in individual interviews were asked to describe situations that resulted in successful outcomes for the parent, the child or the whole family and to identify what they think led to that success. Case files from the CMHT, CSC and voluntary agencies were scrutinised in each case study to allow for comparison with interview responses. The findings from the interviews and documentary evidence about the notion of success were then presented in three semi-structured group interviews with family members, practitioners and managers recruited from the same agencies, to gather further inter-subjective perspectives on what constitutes success and the components leading to it (see Diagram 2).

The research questions are:

- How do different stakeholders (parents, children, professionals) define success?
- What tangible, sustainable outcomes do different stakeholders associate with success?
- How do different stakeholders describe their role in achieving successful outcomes?

- How do different stakeholders describe other people's roles in achieving successful outcomes?
- What do stakeholders see as the major opportunities in achieving success?

Diagram 2: Research design



ONTOLOGICAL AND EPISTEMOLOGICAL ASSUMPTIONS

Researchers bring their own world views, or sets of beliefs, to the research study, and these inform the conduct and writing of research. These beliefs have been called paradigms, philosophical assumptions, epistemologies, and ontologies. These philosophical assumptions consist of a stance toward the nature of reality (ontology), how the researcher knows what she or he knows (epistemology), the role of values in the research (axiology), the language of research (rhetoric), and the

methods used in the process (methodology) (Creswell, 2007). It is important to be aware of the philosophical debates and the methodological developments arising from them at the outset of the research process, in order to secure the quality of the research produced (and therefore the degree to which its findings are accepted, and by whom) (Ritchie & Lewis, 2004). We will now look at each of these in more detail.

Ontology

Ontology relates to the nature of reality and its characteristics. There are two opposing ontological traditions. Heraclitus, (c.535–c475BC) who lived in Ephasus in ancient Greece, placed an emphasis on a changing and emergent world. Parmenides (c.515–c.445BC), who succeeded him, placed quite a different emphasis on a permanent and unchanging reality. Between a Heraclitean ontology of *becoming* and a Parmenidean ontology of *being*, it is the latter that has held sway in Western philosophy (Gray, 2006). This study holds the perspective of a '*being'* ontology. It focuses on exploring different perceptions of success and the components leading to success in parental mental health and child welfare work. It will report on the multiple subjective and inter-subjective realities of children/young people, parents and the staff who work with them. It assumes that the social reality investigated is a product of individual cognition 'created by one's mind' and not external to individuals (Cohen & Manion, 1994). This ontological assumption has informed my choice of methodology which focuses on the meaning attached by stakeholders to the reality as they see it.

Epistemology stances

Epistemology is concerned with the very basis of knowledge – its nature and forms, how it can be acquired, and how communicated to other human beings. Burrell and Morgan, (1979, cited in Cohen & Manion, 1994 p.6) ask:

> *'whether it is possible to identify and communicate the nature of knowledge as being hard, real and capable of being transmitted in tangible form, or whether "knowledge" is of a softer, more subjective, spiritual or even transcendental kind, based on experience and insight of a unique and essentially personal nature'.*

The epistemological assumptions in these instances determine extreme positions on the issues of whether knowledge is something which can be acquired on the one hand, or is something which has to be personally experienced on the other. How one aligns oneself in this particular debate profoundly affects how one will go about uncovering knowledge and social behaviour (Burrell & Morgan, 1979).

Positivism

Positivism is an approach to social research which seeks to apply the natural science model of research to investigations of the social world. It is based on the assumption that there are patterns and regularities, causes and consequences in the social world, just as there are in the natural world. These patterns and regularities in the social world are seen as having their own existence – they are real. For positivists, the aim of social research is to discover these patterns and regularities by using the kind of science methods used to such good effect in the natural sciences (Denscombe, 2005; Gray, 2006). Ideas only deserve their incorporation into knowledge if they can be put to the test of empirical experience (Gray, 2006). The positivistic tradition emphasises the natural sciences methodology as the only scientific methodological framework and assumes an external world about which an unbiased observer might discover abstract generalities that could explain empirical phenomena (Morse, 2009). Playle (1995) argues that positivism offers limited data that provides only an external view of the research phenomenon. It does not provide the ways to examine individuals and their behaviours in an in-depth way.

Interpretivism

Interpretivism is based on a being ontology (Gray, 2006) it looks for 'culturally derived and historically situated interpretations of the social life-world' (Crotty, 1998). Interpretivism is a paradigm for the qualitative analysis of a phenomenon based on how it was experienced by individuals. It focuses on the uniqueness of an individual's thoughts and perceptions, rather than trying to provide objective descriptions. Hence, a social researcher has to explore and understand the social world through the participants and their own perspectives; and explanations can only be offered at the level of meaning rather than cause (Ritchie & Lewis, 2005). Interpretivism recognises the self-reflective nature of qualitative research and emphasises the role of the researcher as an interpreter of the data and an individual who represents

information. It is interpretive because the researcher is engaged in selecting a specific meaning/s in their analysis of a particular research question. It draws on multiple methods to capture as much of an experience as possible, while discovering and verifying theories. Within the interpretive paradigm, there are numerous methodologies for constructing knowledge, each of which has its own underlying philosophies and methods of interpretation. It also acknowledges the importance of language and discourse in qualitative research, as well as issues of power, authority, and domination in all facets of the qualitative inquiry (Gray, 2006; Seale, 1999, Creswell, 2007).

Researcher bias and reflexivity

There are criticisms of the interpretivist approach levelled at researcher bias. Lincoln and Guba (1985, p108) postulate that:

> *'we need to recognise that objectivity in its pure form is an unattainable state (it would in fact be attainable only if there were a single, tangible, reality "out there", a contingency denied in the first axiom of the naturalistic paradigm)'.*

However, they say we should not conclude from this that balance and fairness are not worth striving for, even though one may fall short of their full attainment. Malterud (2001) argues that contemporary theory of knowledge acknowledges the effect of a researcher's position and perspectives, and disputes the belief of a neutral observer. Hence, in qualitative inquiry, the question is neither whether the researcher affects the process nor whether such an effect can be prevented. This methodological point has been turned into a commitment to reflexivity. More detail about how this is reflected in this research can be found under *Confirmability* later in this chapter.

Inductive and deductive reasoning

There is also epistemological debate about the relative merits of induction and deduction. In logic and in data collection and analysis, we refer to the two broad methods of reasoning as the deductive and inductive approaches.

The inductive process

Through the inductive approach, plans are made for data collection, after which the data are analysed to see if any patterns emerge that suggests relationships between variables. From these observations it may be possible to construct generalisations, relationships and even theories. Through induction, the researcher moves carefully towards discovering a binding principle. To ensure a degree of reliability, the researcher often takes multiple cases or instances, through, for example, multiplying observation rather than basing conclusions on one case. The inductive approach does not set out to corroborate or falsify a theory. Instead, through a process of gathering data, it attempts to establish patterns, consistencies and meanings (Gray 2006).

Deductive process

Deductive reasoning is essentially opposite to inductive reasoning working from the more general to the more specific. The deductive approach moves towards hypothesis testing, after which the principle is confirmed, refuted or modified. These hypotheses present an assertion about two or more concepts that attempts to explain the relationship between them. Concepts themselves are abstract ideas that form the guiding blocks of hypotheses and theories. The first stage, therefore, is the elaboration of a set of principles or allied ideas that are then tested through empirical observation or experimentation. But before such experimentation can take place, underlying concepts must be operationalised (made measurable) in such a way that they can be observed to confirm that they have occurred. Hence, measures and indicators are created (Gray, 2006).

Combining the inductive and deductive methods

Inductive and deductive processes are not, however, mutually exclusive. Induction looks for patterns and associations derived from observations of the world; deduction generates propositions and hypotheses theoretically through a logically derived process. Although qualitative research is often viewed as a predominantly inductive paradigm, both deduction and induction are involved at different stages of the qualitative research process. This research uses combined inductive and deductive methods, moving back and forth between them during different stages of the research process, for example: during the literature review key themes and concepts

about success were uncovered – these were then used to formulate interview protocols for the pilot interviews; amendments were made in light of what was learnt during the pilot. Then after the first phase of data collection (individual interviews and file reviews) are completed, the emerging themes from this part of the research are brought together and presented as '*notions of success and the components leading to success'* to the focus groups in the final data collection phase for their further inter-subjective views.

RESEARCH METHODOLOGY

As we have seen above, the positivist and the interpretivist paradigms rely on different assumptions about the nature of the world, they require different methods and procedures to find the type of data wanted as described. This does not mean, however, that the positivist never uses interviews nor that the interpretivist never uses a survey. The difference between qualitative and quantitative research is based on philosophical grounds as discussed earlier in this chapter. Quantitative methods are generally associated with the empirical positivist approach, whereas qualitative methods are associated with post-positivist philosophies such as interpretivism, ethnography and/or phenomenology.

Quantitative research

Quantitative researchers collect facts and study the relationship of one set of facts to another. They measure, using scientific techniques that are likely to produce quantified and, if possible, generalisable conclusions. Quantitative research is concerned with frequency, averages, percentages, and can be analysed by statistical methods (Fuller & Petch, 1995). Central to answering questions and hypotheses is the examination of relationships between and among variables. Quantitative approaches espouse many of the principles of positivism, which the researcher has already rejected as a theoretical paradigm for the study.

Qualitative Research

Qualitative researchers are concerned to understand individuals' perceptions of the world. They seek insight rather than statistical analysis. They doubt whether social 'facts' exist and question whether a 'scientific' approach can be used when dealing with human beings. Yet there are occasions when qualitative researchers draw on

quantitative techniques, and vice versa. There is no single, accepted way of doing qualitative research. How researchers carry it out depends upon a range of factors including their beliefs about the nature of the social world and what can be known about it (ontology), the nature of knowledge and how it can be acquired (epistemology), the purpose(s) and goals of the research, the characteristics of the research participants, the audience for the research, the funder's of the research, and the position and environment of the researchers themselves. The difference and mix of these factors have led to distinctive approaches to qualitative research and this has made it difficult to attain an all-inclusive definition. However, there is agreement on common elements associated with qualitative research, as set out by Ritchie & Lewis (2004) in Box 1. Qualitative methods are used to address research questions that require explanation or understanding of social phenomena and their contexts. They are particularly well suited to exploring issues that hold some complexity and to studying processes that occur over time.

Box 1

- aims which are directed at providing an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives and histories – samples that are small in scale and purposively selected on the basis of salient criteria
- data collection methods which usually involve close contact between the researcher and the research participants, which are interactive and developmental and allow for emergent issues to be explored
- data which are very detailed, information rich and extensive
- analysis which is open to emergent concepts and ideas and which may produce detailed description and classification, identify patterns of association, or develop typologies and explanations
- outputs which tend to focus on the interpretation of social meaning through mapping and 're-presenting' the social world of research participants.

(Ritchie & Lewis, 2004)

<u>Advantages and disadvantages of qualitative research</u>

Qualitative methods are helpful not only in giving rich explanations of complex phenomena, but in creating or evolving theories or conceptual bases, and in

proposing hypotheses to clarify the phenomena. The value of qualitative research consists in validity of the information received; people are minutely interviewed so as to obtained data would be taken as correct and believable reports of their opinions and experiences. A disadvantage is that the data collection and analysis can be time consuming and expensive and this can result in smaller groups being researched which in turn makes the findings less easily transferable.

Mixed methods

Although Lincoln & Guba (1985) perceive qualitative and quantitative approaches as incompatible, Patton (1990) believes that a trained researcher can effectively combine approaches. Creswell (2007) advocates pragmatism about what will produce the best understanding of a problem. This allows researchers the freedom to select from both quantitative and qualitative approaches to choose techniques that best fit the needs and progress of a study, as long as there is a unifying rational or framework. Using mixed methods can enrich what is essentially a qualitative study by magnifying the significance of meanings with descriptive statistics (Creswell, 2007**).** This study is not a mixed methods study but does include numerical data that is not about ranking, but about illustrating the similarities and differences between what different participants groups (parents, children, professionals) had to say.

Validity

The nature of knowledge within the rationalistic (or quantitative) paradigm is different from the nature of knowledge in the naturalistic (qualitative) paradigm. Many perspectives exist regarding the importance of validation in qualitative research: the definition of it, terms to describe it, and procedures for establishing it. Those working within the naturalistic paradigm have questioned the issue of using *validity*, *reliability* and *generalisability* to demonstrate robustness of qualitative research. Lincoln and Guba (1985) suggest that human behaviour is related to context and that the value of data depends on *trustworthiness* which will convince an audience that findings of an inquiry are worth taking account of. In qualitative research the criteria for *trustworthiness* are *credibility, transferability, dependability* and *confirmability*. The table below shows a comparison between quantitative and qualitative research concepts and terms followed by a description of each of the qualitative terms.

Table 1: Quantitative and qualitative research concepts

TABLE 1		
PRINCIPLE	**QUANTITATIVE RESEARCH**	**QUALITATIVE RESEARCH**
Truth Value	Internal Validity	Credibility
Applicability	External Validity	Transferability
Consistency	Reliability	Dependability
Neutrality	Objectivity	Confirmability

(Lincoln & Guba, 1985)

Credibility

I (researcher) have previous experience of working in the field of enquiry as a Community Mental Health team manager and social worker (for nearly twenty years) and as a research and development worker in the field of parental mental health and child welfare. I had previous established links with the organisations taking part in the research site. I also spent a considerable amount of time in the research setting prior to and during data collection. These combined experiences helped me to develop an in-depth understanding of the phenomena being researched, thus enhancing the credibility of the research (Gray, 2004). I involved, and worked with, parents, young people and practitioners in the design of the research, for example agreeing a research working definition of success; and the formulation of data collection tools including participant information sheets and interview protocols. Participants in the research were also asked to verify verbatim transcripts of their interviews to check their accuracy and make amendments. All of these actions signal the approach I have taken to ensure and demonstrate credibility.

Transferability

Qualitative research is regarded by some with scepticism, accused of its subjective nature and the absence of facts. Amongst the main criticisms are the reliability of the method to produce findings that are widely generalisable and the reliability of the researcher being able to operate in an objective and unbiased way. In qualitative inquiry, the aim with respect to external validity is to ascertain whether or not the study hypothesis or results can be applied in other settings and to set out what those

contexts and settings are. Therefore, presentation of contextual background material, such as demographics and study setting, is necessary if the reader is to be able to ascertain for which situations the findings might provide valid information (Malterud, 2001). There are techniques the researcher can employ that, whilst falling short of guaranteeing balance and fairness, can nevertheless provide a system of useful checks and balances (Lincoln & Guba, 1985: Malterud, 2001). For example, detailed accounts of the research setting and rich and in-depth information about the case studies enhance reader empathy and understanding (Gray 2004). Using such descriptions and aided by the use of systematic thematic analysis (Braun & Clarke, 2006), this study aims to add to transferability by contributing a deeper understanding of success in parental mental health and child welfare work. In addition, the use of purposive criterion in sampling aims to strengthens transferability by ensuring the most productive sample.

Dependability

> '*Preconceptions are not the same as bias, unless the researcher fails to mention them. If reflexivity is thoroughly maintained, personal issues can be valuable sources for relevant and specific research' (*Malterud, 2001 p.484*).*

Reflexivity concerns the relationship between the researcher and the social world. Contrary to positivism, reflexivity suggests that there is no prospect of the social researcher achieving an entirely objective position from which to study the social world. Researcher reflexivity creates dependability by offering an open and honest dialogue with readers (Gray 2007). The investigator always enters a field of research with certain opinions about what it is all about (Malterud, 2001). Reflexivity starts by identifying preconceptions brought into the project by the researcher; representing previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests.

As a previous employee in the research setting for this study and as someone with extensive experience of the field of enquiry, I need to pay particular attention to setting out for the reader how my experiences impacted on the research prior to and during the research process. My aim is to ‘position’ myself clearly in this study by

ensuring that research decisions and processes are clear and transparent, as dependability is achieved by ensuring that the reader is able to audit the events and the decision trail of researchers (Koch, 2006). To this end, I have set out a detailed account of my beliefs and experience at the start of the thesis – see *chapter 2: Context of the research.* My observations and views (about their effect) have been discussed throughout the study (using my reflective diary, in discussions with peer researchers and other stakeholders, and in research supervision) within a discussion framework about the limitations and strengths of the enquiry and the transferability of findings:

> '*Bias, in the sense of undesirable or hidden skewness, is thus accounted for, though not eliminated. Subjectivity arises when the effect of the researcher is ignored*' (Malterud, 2001, p.484).

Confirmability

Two techniques used for establishing *confirmability* used in this study are triangulation and the keeping of a reflexive journal. Triangulation is a holistic approach, which enhances the credibility of the findings by the use of several methods at once, so that the biases of any one method might be cancelled out by those of others (Seale, 1999). This study looks at different stakeholder perspectives of success using a number of different methods i.e. interviews, file reviews, semi-structured interviews.

Summary

The above section sets out the philosophical and theoretical assumptions underpinning this study and the rationale for choosing a qualitative methodology as the most effective method for collecting data, on a phenomenon that depends heavily on interpretation of reality from the perspectives of different stakeholders. The next section of this chapter discusses the methodology that has been chosen for the study and why that choice was made.

METHODOLOGY

The chosen methodology for this research is a *multiple embedded case study* drawing on aspects of *realist evaluation*. The multiple embedded case study methodology is outlined below with an explanation of how this methodology *fits* with the philosophical and theoretical stances that the researcher brings to the research project and with what the research is trying to find out about.

Realist evaluation

Parental mental health and child welfare work is complex. The social context for this area of practice is complex. Family roles, functions, and compositions are complex. Evaluating what constitutes success in this context is complex. The aim of this research has always been to first contribute to the identification of what *success* actually means for parents, children and professionals and what the components (content, mechanisms and outcomes) are for achieving this. And secondly, to explore whether there is a conceptual and theoretical framework that can be understood and applied by professionals from all agencies (adult and children's health and social agencies from all sectors) to help to reach a shared understanding of success in parental mental health work; what it looks like, how it can be achieved together and how it can be evaluated.

The term 'r*ealist evaluation'* is drawn from Pawson and Tilley's work, *Realistic evaluation* (1997). It is, as its name suggests, an approach grounded in realism; a school of philosophy which asserts that both the material and social words are 'real' and can have real effects, and that it is possible to work towards a closer understand of what causes change. Pawson and Tilley (1997) argue that many social policy interventions are highly complex, and vary depending on the context in which they are implemented. They argue that the local context that would be regarded as a confounding factor in an experimental design is in fact intrinsic to the way the programme works, and in determining its success or failure. They also argue that greater attention must be paid in evaluation to describing the contexts in, and mechanisms by, which a particular intervention operates. They term this 'realistic' and, later, 'realist' evaluation. The realist approach has particular implications for the design of an evaluation and the roles of participants. For example, rather than comparing changes for participants who have all undertaken a program with a group

of people who have not (as is done in random control or quasi-experimental designs), a realist evaluation compares mechanisms and outcomes with programs or interventions. It may ask, for example, whether a program works differently in different localities or settings (and if so, how and why); or for different population groups (for example, parents and children, for the whole family, for people with differing socio-economic status). Pawson and Tilley argue that different stakeholders will have different information and understandings about how interventions are supposed to work and whether they in fact do so. Data collection processes (interviews, focus groups, and so on) should be constructed to collect the particular information that those stakeholder groups will have, and thereby to refute or refine theories about how and for whom the intervention 'works'. These aspects of realist evaluation are sympathetic to the aims and beliefs underpinning the design of this research and more importantly can make a valuable contribution in this study for thinking in new ways about parental mental health and child welfare work and evaluating outcomes.

Multiple- embedded case study

Case study research is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases over time, through detailed, in-depth data collection involving multiple sources of information (e.g. observations, interviews, audiovisual material, and documents and reports), and reports a case description and case-based themes (Creswell, 2007). The different methods used aim to capture the meaning that people attach to experiences and outcomes for them. A holistic case study is shaped by a thoroughly qualitative approach that relies on narrative, phenomenological descriptions. Themes and hypotheses may be important but should remain subordinate to the understanding of the case (Stake, 1976). See Box 3 for a summary of the general characteristics of case study research.

An embedded case study is a case study containing more than one sub-unit of analysis (Yin, 2003) and the identification of sub-units allows for a more detailed level of inquiry. Similar to a single case study, an embedded case study methodology provides a means of integrating quantitative and qualitative methods

into a single research study (Scholz & Tietje, 2002; Yin 2003). See Box 3 for a summary of the characteristics associated with a case study.

Box 3

BOX 3 CASE STUDY RESEARCH CHARACTERISTICALLY EMPHASISES		
Depth of study	rather than	Breadth of study
The particular	rather than	The general
Relationships/processes	rather than	Outcomes and end-products
Holistic view	rather than	Isolated factors
Natural settings	rather than	One research method

(Denscombe, 2005)

Advantages of a multiple embedded case study approach

The multiple embedded case study methodology is an empirical form of inquiry appropriate for descriptive studies, where the goal is to describe the features, context, and process of a phenomenon. It is a research strategy that comprises an all-encompassing methodology – covering the logic of design, data collection techniques, and specific approaches to data analysis (Yin, 2003). The unique strength of this approach is the ability to combine a variety of information sources including documentation, interviews, and artefacts (e.g. technology or tools). It brings together a range of data to a point of understanding through triangulation which contributes to the validity of the research by permitting the weaknesses and strengths of data collection methods to be balanced (Cheetham, 1996).

> *'By analogy, triangular techniques in the social sciences attempt to map out, or explain more fully, the richness and complexity of human behaviour, by studying it from more than one standpoint and, in so doing by making use of both quantitative and qualitative data.' (Cohen & Manion, 1994, p233).*

The approach allows the researcher to deal with the subtleties and intricacies of complex social situations; enabling the researcher to grapple with relationships and social processes in a way that is denied to the survey, for example. This approach is ideally suited to the complex interplay of factors that exist for families affected by mental illness and the complicated context in which parental mental health and child

welfare work takes place. The analysis is holistic rather than based on isolated factors. The case study approach can fit in well with the needs of small-scale research through concentrating effort on one research site (or just a few sites) as is the case with this research.

Disadvantages of the embedded case study approach

The case study approach is accused of lacking the degree of rigour expected of social science research. This tends to go alongside the view of case study research as focusing on processes rather than measurable end-products, as relying on qualitative data and interpretive methods rather than quantitative data and statistical procedures. None of this is necessarily justified, but it is a preconception which the case study researcher needs to be aware of, and one which means that investigators must exercise great care in designing and doing case studies to overcome the traditional criticisms of the method (Yin, 2003). See earlier section in this chapter on '*validity*' for related information.

Negotiating access to case study settings can be a demanding part of the research process. Research can flounder if permission is withheld or withdrawn. Access to documents, people and settings can also be problematic. Because case study research tends to involve protracted involvement of the researcher over a period of time, there is also the possibility that the presence of the researcher can lead to the *observer effect*. Those being researched might behave differently from normal owing to the knowledge that they are 'under the microscope' and being observed in some way (Denscombe, 2005). There was more likelihood of the *observer effect* occurring in this research because I had previously been employed as a service manager in the research setting. This raised the potential for those who knew me in my previous role feeling doubly scrutinised, which in turn increased the likelihood that they would behave differently. Details about how these aspects of the research were experienced can be found in the next chapter '*Methodology in action'* and further details about the context in which the research takes place and relationship with the research site can be found in *chapter 2: The context of the research.*

Rationale for using a multiple embedded case study approach

The background to this study and the research setting is complex. The case study approach focuses on relationships and processes based on the premise that to understand one thing it is necessary to understand many and others and crucially, how the various parts are linked. A multiple embedded case study methodology has been chosen for this study because it enables the researcher to study things in the detail needed to unravel the complexities of the situation being studied. It provides a holistic approach to describing the detailed workings of the relationships and social processes involved in researching success in parental mental health and child welfare work rather than restricting attention to the outcomes from these.

THE RESEARCH DESIGN

This study is an exploratory case study as it is the first ever study to explore *success* with this specific population. It covers a diverse population that is: different family members; different cultural and ethnic backgrounds; parents with different mental health diagnoses; and statutory and voluntary sector agencies. It is important to cover diversity in this case, in terms of uncovering different opinions of success both in outcomes and processes rather than to ensure applicability of the findings to all families in which there are parents experiencing mental illness. Exploratory case studies usually precede a final study, which can, itself, be a case study, but it can also have a different research design (Boos, 1992). Exploratory case studies help to gain insight into the structure of a phenomenon in order to develop hypotheses, models, or theories (Scholz & Tietje, 2002).

Location of research

As an exploratory study this research covers a diverse population, that is: different family members from different cultural and ethnic backgrounds; parents with different mental health diagnoses; and statutory and voluntary sector professionals from adult and children's health and social care services. The main issue here is to cover diversity in terms of learning different opinions of success both in outcomes and processes rather than to ensure applicability. Given what is also known about the over-representation of some BME groups in mental health and statutory child care

services and the relationship between psychiatric disorders, various measures of poverty and the close links between deprivation and poor health – see *chapter 3: A review of the literature,* it was important that a study site population offered the opportunity for identifying families that met some or all of these criteria. Making sure that the research site was accessible to me (researcher) was also important, particularly as I was in full time work and therefore needed to optimise my research time as much as possible.

Details about the research site/s recruited, the organisations taking part in the research and the community and policy context in which these services are delivered can be found in the *Context chapter* earlier in this thesis. Information about what is already known about barriers and enablers to successful practice can be found in chapter 3 – *A review of the* l*iterature* and in the chapter following this chapter – *Methodology in action,* a fuller discussion can be found about the working with the agencies in the research site, recruitment to the study and the decision to include a second research site.

Sampling

A sample is a finite part of a statistical population whose properties are studied to gain information about the whole (Webster, 1985). Sampling strategies in qualitative research are not viewed as rigid as in quantitative research, however an adequate sample size and information concerned the sampling technique are essential to the development of theories and the presentation of credible conclusions.

Criterion purposeful sampling

Purposeful sampling selects information rich cases for in depth study. Size and specific cases depend on the study purpose. There are about 16 different types of purposeful sampling, for example: criterion; snowball; opportunistic; and intensity sampling (Patton, 1990). Criterion sampling combines various sampling strategies to achieve the desired sample. This helps in triangulation, allows for flexibility, and meets multiple interests and needs. Criterion purposive sampling was selected as the most reliable approach to meet the theoretical aims and needs of this study.

Recruitment to the study

Recruitment started with family members identified in the two participating voluntary sector projects in Lewisham which support parents with mental health problems and their children (the Family Action Building Bridges Project and Family Health ISIS). The assistance of the staff in the two voluntary sector agencies was secured to help to identify and recruit service users who believe they meet the research criteria and were are willing to take part. The cases are essentially self-selected, therefore it may be difficult to have a representative sample. Access to professional gatekeepers appears to be facilitated if researchers can clearly communicate the purpose and value of the research, the trustworthiness of the researchers, and steps that will be taken to minimize any risk of harm from participation (Harker, 2002). Prior to recruitment I spent a considerable amount of time in both participating voluntary sector agencies in order to familiarise staff and service users about the project and to gain the support of staff in identifying and recruiting families to take part in the study. Service users would have already developed a relationship with these agencies and the active endorsement and involvement of each agency I hoped would go some way to reassure participants who were thinking about taking part or letting their children take part. Cases were selected only where the following criteria applied:

- successful outcomes that meet the research definition of success were demonstrated
- the parent and child had had contact with community mental health and or local authority children and families services for a period of time not less than six months in the 18–24 month period prior to the research, and in this time an assessment of their needs had been completed and interventions had been put into place
- the child was at least nine years of age and parental consent was agreed before a child was approached to take part
- parents and children had access to ongoing support during the research process (it was envisaged that this would primarily come from the voluntary sector agencies acting as gatekeepers to the research).

Sample size

The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size.
An optimum number of 12 cases was sought for the sample, two for the pilot stage and a further 10 following this.

Saturation

The suitability of the sample size is determined by considering theoretical saturation. Morse (1995) proposes that the key for judging sampling are appropriateness and adequacy. Appropriateness is judged by the level of success in facilitating understanding of the research issues or problems; it is guided by the characteristics of the informants and by the type of information required. Adequacy refers to informational adequacy and having data of sufficient quality that is complete, rich and full, relevant and saturated. This infers saturation which can be said to have occurred when information adequacy has been achieved in the research. The more saturated the data, the easier it is to develop theory, and field work should not stop until it is comprehensive, until the theory is convincing and until new information does not further provide insight into the category (Creswell, 2007).

Pilot study

The first two case studies recruited were used for the pilot study. Data collection and data analysis methods were carried out in full with these two cases and this enabled me to identify and make changes to the process and to gain experience of using new data analysis software NVivo. Once this was completed data collection resumed with the remaining 10 cases in the study.

Making sure that participants fully understood what taking part in the research meant for them and that they understood the interview questions was vital to their experience of taking part and to the success of the research. With this in mind, the participant information sheets, consent forms, and interview protocols developed for the pilot were all designed in consultation with staff, young carers and parents from

the Barnardos Action with Young Carers Group in Liverpool. Copies of these documents can be found in Appendices: 3, 4 and 5.

Individual interviews

Following recruitment, individual semi-structured interviews took place with parents, children and the practitioners and managers that were working with each case study family. An adaptation of a tried and tested life events screening tool (Goodyear, et al., 2000) was used to help participants identify life events and relationships that had occurred during the 18-24 months prior to interview. Participants were then asked to explore these events in more detail to identify: which resulted in successful outcomes; what they considered the success to have been; how they and others had contributed to the success they described and anything else that helped to facilitate the outcomes. Interviews were chosen because the research is concerned with establishing objective and subjective responses:

> '…*the interview provides access to what is "inside a person's head", (it) makes it possible to measure what a person knows (knowledge or information), what a person likes or dislikes (values and preferences), and what a person thinks (attitudes and beliefs)'* (Tuckman in Cohen & Manion, 1994, p272).

> Semi-structured interviews allowed some loose structure to enable topics to be included which were considered crucial to the study but also to give freedom for the interviewee to talk about what was of importance to them. This method is targeted, focuses directly on the case study topic, is insightful and can provide perceived causal inferences (Gray 2006) and a pre-agreed framework for discussion which simplifies the process of analysis.

Case file reviews

In the next stage of the study, Community Mental Health team (CMHT) and Children and Family team (C&F) case files pertaining to each case (adult and children's files) were systematically analysed, using the same pre-determined questions used in all of the data collection methods in the study allowing comparisons to be made. The strengths of this data collection method are that the evidence is stable and can be

reviewed repeatedly. It is not created as a result of the case study. The data is event and case specific. It has broad coverage over a long span of time of multiple events and multiple settings (Gray, 2006).

Arrangements were put in place to allow for follow up telephone contact, to organise a follow up interview, or to review a case file again if gaps in the data were identified or to investigate further any issues identified in the earlier stages of the research. In the event this was not necessary.

Semi-structured group interviews

Further comparative data was then collected by conducting three semi-structured group interviews with parents, children and staff from the participating organisations. The organisations assisted in recruiting family members and an invitation to take part signed by the researcher and a senior manager from each organisation was sent to the relevant staff in each agency. The emerging themes from earlier stages of the research were presented and groups were asked to discuss these themes to gather further perspectives on success. Individuals' details and any other identifiable information were carefully anonymised before being presented to group members. Group interviews were chosen to maximise the potential for discussion to develop, thus yielding a wider range of responses (Cohen, & Manion, 1994).

Group interviews, when used effectively, can provide a safe peer environment for children and young people to discuss potentially sensitive issues. However, groups are not appropriate for all children, as some may feel inhibited about speaking in front of a group or fear reprisal and ridicule as a result of their comments and the risk of dominant voices dictating the agenda (Harker, 2002). Therefore, the involvement of children in designing and testing the format of individual and group interviews was an important step in promoting children and young peoples' participation in, and increasing their enjoyment of, the research process. The researcher recruited the support of Barnardos Action with Young Carers Project in Liverpool who provided assistance with the design of the research information sheets and interview schedules.

Organising and analysing the data

I used the computer-assisted qualitative data software NVivo to assist me in identifying themes from the data collected from the individual interviews, group interviews and file reviews. NVivo is a Qualitative Data Analysis (QDA) computer software package produced by QSR International. It has been designed for qualitative researchers working with very rich text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required). NVivo helps to organise and analyse complex non-numerical or unstructured data. The software allows users to classify, sort and arrange thousands of pieces of information; examine complex relationships in the data; and combine subtle analysis with linking, shaping, searching and modelling. It was used in this study because it provided me with the opportunity for a much deeper level of analysis. With NVivo the researcher can test theories, identify trends and cross-examine information in a multitude of ways using its search engine and query functions. The researcher can make observations in the software and build a body of evidence to support the research. One of the limitations of narrative research previously has been that it is difficult to use across a large sample, though this is becoming more manageable with qualitative software like NVivo.

Thematic analysis

Thematic data analysis (Braun, & Clarke, 2006) was applied in this research study. Thematic analysis is a widely used qualitative analytic method. It is a method that involves searching across a data set – be that a number of interviews or focus groups, or a range of texts – to find repeated patterns of meaning. It minimally organises and describes a data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998). The researcher plays an active part in identifying patterns/themes although the passive description of '*emerging' themes* is frequently heard (Taylor and Ussher, 2001). What is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them as decisions.

Thematic analysis involves a number of choices which are often not made explicit, but which need explicitly to be considered and discussed. In practice, these questions should be considered before analysis (and some-times even collection) of the data begins, and there needs to be an ongoing reflexive dialogue on the part of the researcher or researchers with regards to these issues, throughout the analytic process**.** An important question to address in terms of coding is: what as a pattern/theme or what 'size' does a theme need to be? In terms of coding, the questions of prevalence in terms both of space within each data item and of prevalence across the entire data set. But more instances do not necessarily mean the theme itself is more crucial. Rigid rules do not work the researcher needs to retain some flexibility. Furthermore the 'keyness' of a theme is not necessarily dependent on quantifiable measures – but rather on whether it captures something important in relation to the overall research question (Braun and Clarke, 2006). Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data (Braun and Clarke, 2006).

Research diary

To maintain a reflective focus throughout the study, I used a research diary, to reflect upon and record the history of the research as it unfolded and the process of my research skills development. In turn, the diary provided the context for reflecting on the research enabling me to maintain an overview of progress over time which I have been able to use as a reference for what happened when in the process.

ETHICAL ISSUES

People's interests, needs and feelings must not be damaged by the process of evaluation or its outcomes. Social researchers should be ethical. In the collection of their data, in the process of analysing the data and in the dissemination of findings, they are expected to:

- respect the rights and dignity of those who are participating in the research project
- avoid any harm to the participants arising from their involvement in the research

- operate with honesty and integrity.

These principles stem from the belief that people should be protected from researchers who might be tempted to use any means available to advance the state of knowledge on a given topic. The principles rest on the assumption that researchers have no privileged position in society that justifies them pursuing their interests at the expense of those they are studying – no matter how valuable they hope the findings might be *(*Denscombe, 2005). Collection and use of data has also become enshrined in legislation which is another reason why social researchers need to adopt an unscrupulous collection and use of data has become enshrined in legislation. The application for ethical approval for this research was submitted to the London Borough of Lewisham Research Governance Board and the Joint South London and Maudsley/Institute of Psychiatry NHS Research Ethics Committee. Ethical approval was given by both research governance bodies.

Informed consent

People should never be forced or coerced into helping with research. Their participation must always be voluntary, and they must have sufficient information about the research to arrive at a reasoned judgement about whether or not they want to participate. Research participants in the study were given information sheets (Appendix 3) that included: the subject of the research, its aims and objectives, assurances of anonymity and confidentiality, and reassurance that consent to participate is a continuous process by reminding them that they can withdraw at any stage, either temporarily or permanently, with details about how this could be facilitated. The process is also explained verbally to each participant and a signature will be required to indicate that the process has been explained adequately.

For children, it was necessary to gain their parent/guardian's permission for their involvement in the research process. Children were then approached for their consent and care was taken to provide information about the research process in age and ability appropriate formats – by employing the assistance staff and young people from the Barnardos Action with Young Carers Group in Liverpool (details of this organisation can be found in the *Context* chapter).

Confidentiality

Confidentiality was observed by using code names for participants and teams and taking reasonable steps in the write-up to avoid text where individuals or groups might be easily recognisable. Written confidentiality agreements were made with each of the agencies taking part. Transcripts of individual and group interviews were circulated to participants for comment, accuracy and retrospective comments after each event. Electronic files have been password protected; interview tapes are locked in a drawer at the researcher's employer's address. The data will be destroyed six months following the successful completion of the dissertation.

Vulnerable adults and children

Researchers have a moral and ethical obligation to protect research participants from significant harm, both during the research process and as a result of the research (Harker 2002). As parents and children are asked in this study to talk about difficult periods in their lives, it was important to be sensitive and responsive to any signs of distress that adults or children exhibited. Interviews and group discussions therefore needed to be conducted by someone with the necessary interview skills, knowledge and sensitivity to be able to create an interview situation and gather the information needed without negatively impacting on the interviewee. I am a social work professional with twenty years practice experience as a generic worker initially and latterly in adult mental health. In addition to interviewing as a practitioner and manager I have previous experience at post-graduate and Masters level of interviewing vulnerable adults as a researcher. Parents and children/young people were all offered the choice of being interviewed alone or with a member of staff that they were familiar with or a friend. These choices were explained fully on the parent and child research information sheets – see Appendix 3. As I was employed previously in Lewisham as a CMHT manager it was possible that family members identified as potential participants may have had previous contact with me in this role. In the event this did not happen but if it had the family would not have been invited to take part.

I offered all participants including professional staff the opportunity for a detailed debriefing including discussion about opportunities for additional support if they felt the research process has disturbed them in any way, and a follow up contact number

in the event that issues arose at a later date. I understood that some parents and children may prefer to discuss what they spoke about in interview with someone they knew from the agencies taking part. Participants were made aware of the options available before and after interview. I then prepared nominated supporters by alerting them of when the interview was taking place; providing information about the research process; and being available to them should they want to discuss potential impacts that taking part might have. A gift token was offered to parents, children and other family members to thank them for their contribution.

Reporting risk

The research process may elicit disclosures from participants or documentary evidence that has ethical and professional implications, for instance 'dangerous' practice or possible self-harm or harm to others. Details about 'reporting risk' were clearly set out in the participant information sheets and consent forms (Appendix 3 and 4). At the beginning of the research process agreements were reached with participating agencies and participants were all made fully aware of how far there are limits to confidentiality and the steps the researcher would have to take should such information be disclosed or uncovered. Every participant was asked to sign a consent form to confirm that they had received and this information and that they understood it in the context of the research process.

Feedback to participants

Participants were offered the opportunity to receive feedback on research findings and how their views have been reflected. There are a broad range of participants involved in the research and therefore this may require a number of feedback formats to reach different groups and this formed part of the initial discussion when the research sites were recruited. Every participant will receive a written summary of the key findings and arrangements will be made with both research sites to hold a local event where the research findings will be presented and there is opportunity for discussion. Research participants will be invited to attend these events and other interested parties in these localities.

In summary

The philosophical and theoretical assumptions underpinning the research and the research design have been set out in this chapter. The theoretical background to, and the rational for the methods of data analysis were explained, and the research site, sampling strategy and ethical considerations were discussed. The next chapter looks at part of the research process in action by setting out the roles that different *gatekeepers* to the research played in the early stages of the research process and the sequence of events that led to the recruitment of a further research site in Liverpool.

CHAPTER 6 - METHODOLOGY IN ACTION

INTRODUCTION

This chapter sets out what took place during the recruitment phase of the fieldwork for this research. It begins with an exploration of the relationship between myself (researcher) and the different gatekeepers to the research. The next part of the chapter looks at the barriers and enablers to recruiting families to the study. The decision to recruit a second research site and the outcomes of doing this are then summarised in the final section of the chapter.

GATEKEEPERS

Gatekeeping is the process of allowing or denying another person access to someone or something (Holloway and Wheeler, 2002). Gatekeeping in research is deliberate; to ensure that vulnerable adults, children and their families are protected and to determine the way that potential research participants are approached and invited to participate. Health and social care professionals can also be considered to be vulnerable if they are asked to participate in research. Therefore they too must be protected from some researchers who may not be scrupulous in adhering to ethical principles. The gatekeeper within health and social care research therefore has some power and control – and responsibility – to protect potentially vulnerable people (Holloway and Wheeler, 2002).

The process of gatekeeping

Gatekeepers are first encountered during the process of gaining access to the proposed research site. Gatekeeping can also occur at other stages in the research process, and can cause difficulties if it is done improperly. However, a number of strategies can be employed to avoid or at least minimise these potential difficulties.

Organisational and professional gatekeepers

Researchers understand that access to a research site, which may include vulnerable adults, children, their families or professional care givers, is an important ethical issue within research proposals and therefore an element of gatekeeping must be involved. Initially, therefore, they must identify the key gatekeepers

concerned (Polit et al., 2001) and focus attention on gaining their support (Holloway and Wheeler, 2002).

Benton and Cormack (2000) suggest that the key gatekeepers are at both an organisational and a professional level and this is the same within social care research. The organisational gatekeepers for this research are the research and development coordinators for the NHS trust, the local authority and the two voluntary sector agencies. These organisation gatekeepers have a duty to be aware of research taking place within their organisation and to ensure that the research meets the required ethical standards. The professional gatekeeper(s) for this research are the nominated managers in each service as involvement of staff, service users and access to service user records is required. These professional gatekeepers need to be convinced that the research is credible and that the researcher is competent (Benton and Cormack, 2000). Where there is a layer of professional gatekeepers, as there is in this research study the researcher will need to keep them all informed to obtain and maintain access to the proposed research site.

From the outset I was aware that the agencies targeted to take part in the research process received frequent requests to take part in research and development activities. I knew too, that senior managers in these organisations who I needed to approach to get permission to undertake the research in their organisations would be wary of the impact on their staff of taking part and on service delivery. Therefore it was important to allocate enough time and attention to establishing relationships with these organisation gatekeepers. As well as aiming to convince them about the merits of the research, I made sure I was as flexible as possible to fit in with their busy professional timetables and in my negotiations about how the research could be conducted with the minimum disruption to staff and service delivery.

In January 2008 I wrote to a senior manager in each of the four identified agencies with details about the research proposal, draft letters of invitation to the research participants and a request to meet with each of them to discuss the research in more detail. After meeting with each of the agency representatives individually I then met with all four together. All four gatekeepers were interested in the research topic and because of their prior knowledge of my professional practice and understanding of

the issues, they expressed their confidence in my ability to undertake the research. However, there were some common concerns about taking part, as follows.

Identifying participants

All of the managers/gatekeepers could think of families that met some of the criteria for inclusion in the research but they were concerned that it might be difficult to find enough families that met all of the research criteria. In particular, they thought it would be difficult to find families that were in contact with children's social care, a community mental health team and one of the voluntary sector agencies for the period specified in the research criteria. The gatekeepers agreed to talk to their teams to get a rough indication of the number of families who would be eligible to take part using the existing criteria.

Facilitating engagement

The gatekeepers from the statutory agencies in particular wanted to impress upon me the considerable workload pressures that their staff were under and wanted to be clear about how much time staff invited to take part in the research would need to commit. I was able to give a reasonably accurate estimate of the staff time needed and together we identified strategies to ensure professional staff input was kept to what was absolutely necessary. For example, I offered to travel to staff participants wherever they were located. We negotiated that access to records would be facilitated by one CMHT administrator that I would liaise with rather than the CMHT case worker. I was also very aware that the managers themselves were busy and I drafted letters for them to send to staff and senior managers about the research, and took responsibility for arranging meetings, taking minutes and circulating them. In the following months I met with the nominated management group to discuss the research and do the groundwork that was needed to try to ensure that data collection could begin as soon as ethical approval was given, and so that any potential problems could be identified and dealt with.

Being under scrutiny

Two of the gatekeepers felt able to express their concerns that the research (or perhaps I as a fellow professional) would uncover some aspects of practice that they would be embarrassed about. For example, the gatekeepers from children's social

care and community mental health were unsure whether their case records would easily enable them to identify whether families were known to each other's services. Because of this they agreed to meet to meet separately to compare their audit of potential case participants. Children's social care were also concerned about the impact of any research findings that are critical of services, given that there had been a number of recent serious and untoward incidents involving parental mental health issues that were still fresh in staff members' minds. In response, I tried to reassure gatekeepers on several occasions and in writing (participant information sheets) that the focus of this research was about success.

Conceptualising success

The single most difficult issue was reaching a shared understanding of the research definition of 'success' and for that to be communicated effectively between professional gatekeepers, their staff and ultimately potential family participants. There appeared to be a number of factors that contributed to this dilemma. The first was it was unfamiliar for some gatekeepers to be adopting a notion of success that was not associated with clinical or service outcomes or situations where 'everything was better'. There was also a lot of discussion about whether parents in particular would identify success in the same way that staff would and that families were more likely to be critical of agency involvement than positive. On several occasions I tried to reassure and reiterate that I was interested in finding out about different perceptions of success and the starting point for identifying the case studies would be family members who considered that they had experienced some lasting positive change or success. Reflecting on what parents and young people might have to say and what agencies might have to say about each was a an issue that was raised frequently in early meetings with gatekeepers.

In response, I prepared criteria for identifying success for gatekeepers in the voluntary sector agencies and a range of examples of situations that parents and children might associate with success. However, this issue remained the most discussed and the least easy to resolve throughout the recruitment process.

GAINING ETHICAL APPROVAL

Professional gatekeepers must be given sufficient information to enable them to make an informed decision as to whether to grant permission for the researcher to proceed to their local research ethics committee/s. All four agency gatekeepers agreed that their organisations would take part in the research. Confirmation of this was sent to the relevant Local Research Ethics Committee (LREC) and Research and Development Groups (RDGs) to enable me to progress formal applications for research and ethical approval. I reached agreement with the professional gatekeepers that we would continue to meet regularly until the recruitment phase of the fieldwork was completed and thereafter at key points throughout the rest of the process. This was to help facilitate access to research participants and to enable a speedy response to any unexpected problems should they arise.

Ethical approval

I completed and submitted the local authority and NHS ethics applications with copies of the participant information sheets, interview schedules, consent forms and research timetable. Liaising with the voluntary sector agencies about gaining ethical approval was straight forward and approval was given very quickly. My application to the local authority was approved with some provisions; namely that I should report back to the local authority with the outcome of the pilot study before proceeding with the focus groups. The application and process for seeking NHS approval was particularly arduous and very time consuming. I completed a very full application, I asked the LREC coordinator to look over it before I submitted and I attended the committee meeting to answer any questions that they might have. Despite a great deal of effort it was still very difficult to achieve a 'fit' for a qualitative study. This was particularly apparent in the questions asked at the committee meeting. Several of the committee were clearly unfamiliar about studies within the naturalistic paradigm and the methods used to collect qualitative/data.

Just as key gatekeepers may refuse permission to access the research site, the ethics committee may do the same. My first submission to the NHS was declined in July 2008. A further submission was made that was accepted on the 7 November 2008. It was several more months before I received my Honorary NHS Research Contract.

Research approval and further issues

During the lengthy wait for research approval I maintained contact with the agencies in the research site. I met with other members of staff in the different agencies to talk to them about the research. It became clear that, as suspected by the professional gatekeepers at the outset, it was not going to be possible to recruit enough families that met all of the research criteria. The professional gatekeepers were particularly helpful at this stage in helping me to amend the criteria to increase the opportunities for recruitment. However, after amending the inclusion criteria twice, first to reduce the number of agencies a family needed to be in contact with, and secondly widening the recruitment role to include all four agencies, there were still very few families identified.

Five families were identified from the voluntary sector agencies but only one of these families was invited and took part. The other four did not get past the second level of gatekeepers – that was their key workers. Each of the four parents was initially willing to take part when the professional gatekeepers (the managers of the project) discussed the research with them. However, when I met with the key workers to arrange interviews I was told that one parent had changed their mind and did not want to take part after all; and that two parents, on reflection (the key worker's refection), did not meet the research criteria after all. When I explored this further during a meeting with the key worker for two of these parents I was told that the parents, in her opinion, would not be able to give me what I needed as a researcher. I was also told by the same worker that as a white person I might have difficulty in getting some of their service users (who are all African or African Caribbean) to speak to me. The key worker for the fourth parent that had originally agreed to take part told me that the service user/parent was experiencing a difficult time and she did not feel it was in the service user's best interest to take part.

Once the eligibility criteria was relaxed to allow the two statutory agencies to approach parents and young people they expressed similar concerns. Managers identified a number of families but it was then difficult to negotiate access via their key workers. When families were identified the key workers were reluctant to extend an invitation. Some practitioners were reluctant to make introductions for fear that

parents would become unsettled or upset if they were asked questions about their parenting and their children. One Community Mental Health Team did identify two more parents, who they invited to take part, making three families in total. It was difficult even at this preliminary stage of screening to find families who met the research criteria, because practitioners and key workers found it hard to identify success. They were also concerned that families themselves may not be able to identify that any success or positive change had occurred for them or that they would only be critical of agency input.

I had not envisaged that it would take as long as it did to gain ethical approval or to recruit families to take part. The additional time taken for both processes together amounted to a delay in the research timetable of approximately 12 months and still I had not recruited enough case studies as I was aiming for 10 to 12 in total.

The different layers of gatekeeping did pose a number of issues that were difficult to surmount despite prolonged effort. I was able to successfully secure a relationship with gatekeepers at an organisational level; however the layer of gatekeepers beneath, that is the key workers for parents and children, were more difficult to negotiate with. In an effort to improve the situation I spent time at team meetings in the voluntary sector agencies to familiarise staff with the research but this was not so easy in the statutory agencies because of the size of the organisations. In addition, it was clear that despite discussing the research on a number of occasions, being available for questions and preparing written information in a number of formats and lengths that managers and staff did not necessarily read or absorb the information. Similarly, when managers were conveying to staff what the research was about, I think a lot got lost in translation. There was the additional problem that practitioners (particularly from the statutory services) had in conceptualising success. In response I involved the organisational gatekeepers in identifying recruitment strategies and they did their best to help. I offered to speak to parents directly at drop-ins in Building Bridges and Family Health Isis but was met with a number of reasons about why this would not be possible. I offered to do some case finding exercises with managers and staff but they preferred to do this themselves and this did result in one CMHT, identifying two parents.

My impression was always that the organisational gatekeepers were doing their best in difficult circumstances (other demands on their time) to assist me. However, I think it was difficult other than immediately after our meetings together or after I had made contact with them between meetings, to keep the research 'in mind' or in the minds of their staff. If I had still been an employee in Lewisham my presence would have made it far easier to keep the research alive.

THE DECISION TO RECRUIT A FURTHER RESEARCH SITE

The three families and the key workers from the agencies that supported them in Lewisham were interviewed and the file information needed for the study was retrieved. After about a year of continually trying to recruit more families, I made the decision in collaboration with my research supervisors and the organisation gatekeepers in Lewisham to increase opportunities for referrals by recruiting a second research site.

I contacted Barnardos Action with Young Carers in Liverpool to find out if they would be interested in taking part and to find out if they could identify families who met the recruitment criteria that could be invited to take part. The organisation was already involved indirectly in the research as they had helped me to put together the research information sheets in ways that were acceptable to parents and young people. Demographically, the populations being researched share largely similar characteristics, although Liverpool is much larger than Lewisham and where there are any differences in context this could be reflected in the study. I received a very positive response from Action with Young Carers and they did think they had more than enough families that they could approach. I then made contact with Mersey Care NHS Trust to see if they were also willing to take part as the Community Mental Health Teams in Liverpool are part of this trust – they also agreed.

I then had to complete a further process of securing ethical and research approval from the original NHS LREC for approval for a further study site to be added and from Barnardos and Mersey Care NHS Trust. It was several more months until I received the necessary additional research and development approvals and honorary contract. The process was more straightforward this time as the proposed

addition did not alter the research design or methodology or the scientific value of the study.

Subsequently Action with Young Carers invited nine families who met the recruitment criteria to take part. They all agreed and I was able to complete interviews with all of the parents, their children and their key workers from Barnardos by the end of June 2010. I then interviewed the parent's key workers in the Mersey Care CMHTs by phone at a later date.

SUMMARY AND REFLECTIONS

Gatekeeping as part of a research project is a complex ongoing process. It requires the researcher to have strong interpersonal skills, a sound understanding of ethical principles and knowledge of who can be approached. On reflection, I do feel the organisational gatekeepers and I did everything possible to recruit families. At the time that recruitment was taking place in Lewisham there were a number of changes taking place for the agencies involved. The mental health trust and local authority were entering a phase of unprecedented reorganisation and all services were being pressured to make considerable efficiency savings including job losses. In contrast whilst Action with Young Carers and Mersey Care Trust were going to be entering a period of further cuts in budgets and resources this had not yet happened. This may have been a contributory factor as to why it was so difficult in Lewisham to get past secondary gatekeepers. However, the most apparent barriers seemed to be the difficulty that professionals had in conceptualising success and imagining what success would look like from a family perspective. It was also difficult for some professionals to believe that many of the families that they had worked with would have positive things to say about agency involvement. In contrast, Action with Young Carers did not have difficulties in understanding what success might look like for individuals and families and they were keen to take part to find out more about what works for families. As a project they are regularly involved in research and development work and encourage user participation in all of these initiatives. As a consequence of these experiences they had developed and established their role as gatekeepers and facilitators to research and this was very obvious and led to the speedy and successful recruitment process in this research site.

In this chapter I have set out what took place during the recruitment phase of the fieldwork for this research and the rationale for the recruitment of a further research site. In the *Context* chapter there are more details about each of the research sites, including details about all of the organisations taking part.

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CHAPTER 7: FINDINGS (1)

INTRODUCTION

This chapter sets out the findings of the research. It begins with demographics of the sample, describing the range of participants and their involvement in the study. Then the findings from the individual interviews with parents, children and professionals are described, starting with different stakeholder definitions of s*uccess* (things that had worked out well or better than previously), followed by the contributions that different stakeholders made to the successes described, and different stakeholder views about the major obstacles to success. The chapter concludes with an analysis of how the two remaining data sources, i.e. the case file reviews and the three focus groups, either corroborate or disagree with the findings set out in this chapter.

UNDERSTANDING THE DATA

Data collection was undertaken in three stages: individual interviews with parents, children and the professionals who support them; a review of the agency case files kept about the same families; and three focus groups: one with parents, one with children and one with a mixed group of professionals. The focus groups were convened to discuss the emerging findings from the first two phases of data collection.

Table 1 gives a breakdown of the interviews that took place with parents, children and professionals in each research site, including the total number in each participant category.

Table 1 – NUMBER OF INDIVIDUAL INTERVIEWS – FIRST STAGE OF DATA COLLECTION			
Participant group	**Lewisham**	**Liverpool**	**Total**
Parents/mothers	3	9	12
Children/young People	1	11	12
Children's Social Care staff	1	0	1
Community Mental Health Team staff	4	2	6
Voluntary sector staff	1	17	18
Total number of participants	**10**	**39**	**49**

Table 2 gives a breakdown of the number of files reviewed from each agency and the total number in each research site.

Table 2 – NUMBER OF FILE REVIEWS – SECOND STAGE OF DATA COLLECTION			
Agency file	**Lewisham**	**Liverpool**	**Total**
Children's Social Care	2	0	2
Community Mental Health Services	3	8	11
Voluntary sector	0	9	9
Total number of files reviewed	**5**	**17**	**22**

*More detail about who was interviewed and which files were reviewed in each of the 12 case study families is set out Appendix 2.

Table 3 sets out how many participants took part in each focus group and from which research site.

Table 3 – NUMBER AND TYPE OF FOCUS GROUP PARTICIPANTS – SECOND STAGE OF DATA COLLECTION			
Focus group	**Lewisham**	**Liverpool**	**Total**
Mixed professional	9 (4 CSC staff (3 Managers and 1 Family Support Worker); 2 CMHT Social Workers; 1 CAMHS Manager; 2 Lewisham Building Bridges Managers)	2 Barnardos Action with Young Carers Managers	11
Parents	0	7	7
Children	0	7	7
Total number of participants	**9**	**16**	**25**

Table 4 describes which of the participating agencies in the research were involved with each case study family (in the two year period prior to and up to the time of the research) and the case status at the time of data collection. Although not a participating agency in either of the two sites, CAMHS services were included in the focus groups (and Table 3) because eight children from six families had significant CAMHS involvement. All of the parents were known to community mental health services, some for many years and all of the children were known to one or more service. Eleven of the twelve families had two or more agencies supporting them at any one time during the two year period prior the research and six families had four or more agencies involved. These figures highlight the complexity of issues that can exist in families and how identifying and responding to complex needs can involve a significant number of agencies and resources.

Table 4 – AGENCY INVOLVEMENT WITH PARENTS AND CHILDREN

Case Study Family Number	Community Mental Health Services	Children's Social Care	Child and Adolescent Mental Health Services	Lewisham Building Bridges	Barnardos Action with Young Carers	Other
CS1	✓	Closed	x	✓	x	✓
CS2	✓	x	x	x	x	X
CS3	✓	✓	x	x	x	X
CS4	✓	x	x	x	✓	✓
CS5	✓	x	✓	x	✓	✓
CS6	✓	x	✓	x	✓	✓
CS7	✓	✓	✓	x	✓	✓
CS8	✓	x	✓	x	✓	✓
CS9	✓	✓	✓	x	✓	✓
CS10	✓	x	✓	x	✓	✓
CS11	✓	x	x	x	✓	✓
CS12	✓	x	x	x	✓	✓

Tables 5a and 5b illustrates the multiple difficulties and high levels of deprivation experienced by the families taking part. The tables include the presenting problems at the time of referral to services and historical events that were still impacting on different family members' lives.

Table 5a – PRESENTING DIFFICULTIES FOR PARENTS (N=12)	
Presenting difficulties	**Number of parents (N=12)**
Low income and in receipts of welfare benefits	12
Experience of psychiatric inpatient treatment	10
Anxiety and panic attacks	10
Domestic Violence	8
Living in poor housing conditions	7
Chronic or serious health problems	7
History of child abuse (sexual, physical, emotional, neglect)	7
Depression including treatment resistant	6
Emotionally unstable personality disorder	6
Substance misuse	6
Ever been employed	5
Overdose and suicidal impulses	4
Anger/aggression/behavioural problems	4
Agoraphobia	3
Obsessive Compulsive Disorder	3
Self harm	3
Antisocial/Violence/Aggression/Forensic History	3
Eating Disorder	2
In local authority care as a child	2
Paranoid Schizophrenia	2
In voluntary employment or in training at the time of interview	2
Bi-Polar Disorder	1
Depression with psychotic symptoms	1
Employed during 5 years prior to interview	0

Table 5b – PRESENTING DIFFICULTIES FOR CHILDREN (N=12)	
Presenting difficulties	**Number of children (N=12)**
Low income and in receipt of benefits	12
Young carer responsibilities	11
Behavioural problems	10
Parent child relationship problems	9
History or child abuse (sexual, physical, emotional, neglect)	9
Living in poor or housing conditions	7
Depression	3
Self harm	3
Chronic or serious health problems	3
Experience of being bullied	3
Engagement in anti-social or criminal behaviour	3
Overdose and suicidal impulses	2
Substance misuse	2
Excluded from formal education	2
Eating disorder	1
Dyslexia, Dyspraxia and Learning Difficulties	1
Teenage pregnancy	1
Been in care	1

Sixty seven per cent of families were White British, then 17 per cent Black British, eight per cent Black-Caribbean and eight per cent Black-African. All of the parents were mothers (36 years to 50 years with a mean of 46 years). There was an equal distribution of male and female children (45 per cent male and 54 per cent female) age ranging from nine years to 24 years, with a mean of 15 years. All families lived in local authority or housing association rented accommodation.

Mothers' status and paternal contact with children are presented in Table 6, from which we can see that nine of the twelve parents are bringing up their children without support from the children's fathers. The table also details whether mothers retain day to day care for some or all of their children.

Table 6 - MOTHERS' STATUS AND PATERNAL CONTACT WITH CHILDREN	
Situation	**Number**
Single with child(ren) with no involvement or problematic involvement with child/ren's birth father	7
Single with child(ren) with positive involvement from child/ren's father	2
Co-habiting with younger child(ren) and in contact with older child living away from home with birth father	1
Single with first child from previous partnership in local authority care and remaining children at home with external support from their birth father	1
Widowed with child(ren)	1

DIFFERENT STAKEHOLDER DEFINITIONS OF SUCCESS

The findings from the individual interviews (n=49) about success are reported next. The interview questions used in the individual and focus group interviews with parents, children and professionals can be found in Appendix 5. All participants were given a research code, to protect identity, and codes are consistent throughout the data, in the appendices and chapters. The codes by participant type are set out in Table 7 for reference.

Table 7 – RESEARCH CODES FOR PARTICIPANTS	
Participant type	**Research code followed by case study number**
Mother	M - e.g. M1
Child	C - e.g. C2
Community mental health team professional (social worker, community psychiatric nurse, occupational therapist)	CMHT – e.g. CMHT1
Community mental health team manager	CMHTMan – e.g. CMHTMan1
Children's Social Care social worker	CSC - e.g. CSC1
Lewisham Building Bridges social worker	BBPrac - e.g.BBPrac1
Barnardos Action with Young Carers social worker	Bar - Bar1
Barnardos Action with Young Carers manager	BarMan - e.g. BarMan1

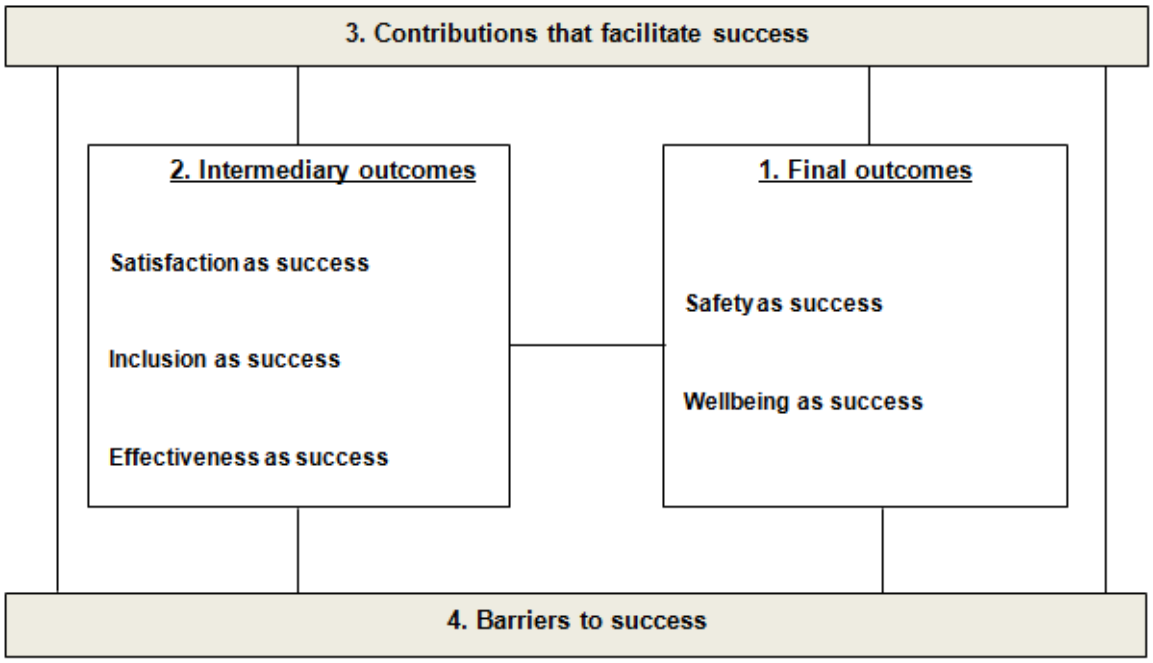
Participants in the study were asked to describe situations that had been successful, or that had worked out better than previously, in the case study families in the two years prior to interview. They were also asked to identify the outcomes that resulted from the successes they described, what had contributed to the successes and what

had got in the way. Sorting and categorising the responses to these questions about: *definitions of success*; *outcomes of success*; *contributions to success* and *barriers to success* was not straightforward. For example whilst one participant described '*getting her medication right*' as an example of success as this led to improved and sustained improvements in her mental health, another parent described her improved mental health as her definition of success. These differences were not attributable to participants not being able to differentiate between experience, process and end results or outcomes. Instead, participants were highlighting that positive experiences, relationships, interventions and processes, warrant a definition of success as much as successes that were about final or end outcomes. And that these different elements of success also interact with each other. In summary, the data analysis identified four overarching and interacting themes (or elements) about determining success:

1. Final outcomes – fundamental differences or changes made for or with children and parents in parental mental health work
2. Intermediary (process) outcomes – impacts which are associated with such changes and/or may assist in bringing final outcomes about
3. Contributions that facilitate success – different stakeholder contributions
4. Barriers to success, that have to be overcome or negotiated to access interventions and reach the successful outcomes described.

Diagram 3 – *Elements of success* has been developed to convey an understanding about how multiple factors within and between individuals, service providers and their environments interact. The interactions between each of the components (research themes) are illustrated by the arrows. They highlight the relevance of a systems approach to understanding the data. Each component affects and is affected by every other component.

Diagram 3 - Elements of success



Illustrative quotations are used to allow the voices of parents, children and professionals to be heard. The number of responses (number of respondents) and number of times mentioned (frequency) are set out in table form at the beginning of each sub-theme. The inclusion of this data is not about ranking, but about illustrating the similarities and differences between what different participant groups (parents, children, professionals) had to say.

FINAL OUTCOMES (1)

The *final outcomes* here are about the fundamental differences or changes that were made for or with parents and children in parental mental health and child welfare work, as described by parents, children and professionals. There are two themes in this category of success (each with their own sub-themes), which are:

a. Safety as success
b. Wellbeing as success

These will now be discussed in turn starting with *Safety as success*.

1a. Safety as success

This section of the findings relates only to those aspects of promoting safety and safeguarding that parents, children and professionals talked about. As a response to concerns about *safety* some parents had been detained (on more than one occasion) in hospital for assessment and or treatment, under Section 2 or Section 3 of the Mental Health Act 1983, and a number of the children in the study had been or were still on the *Child Protection Register* or had been subject to care proceedings. Whilst these situations were discussed, the vast majority of the findings about '*safety as success'* were not about what took place to secure '*immediate safety'* of the parent or the child, they were instead about *minimising risk and risk avoidance* and *family contributions to safety as success* .

Minimising risk and risk avoidance	**Number (percentage) of respondents**
Total number of research respondents who talked about this theme	30 (61%)
Parents who talked about this theme	9 (75%)
Children who talked about this theme	6 (50%)
Professionals who talked about this theme	15 (60%)

Mental health *contingency* and *crisis plans* that are part of the *care planning process* (CPA) in adult mental health that work in smooth uncomplicated ways, were identified by practitioners and parents as an important way of enabling parents to feel more assured that should their mental health deteriorate then help would be readily at hand and easy to access. Whilst the majority of children were not routinely involved the preparation of their parent's *crisis* and *contingency* plans, where this did happen it was extremely reassuring and arguably led to more specific and achievable plans that included attention to the needs of children. A mother talking about a CPA crisis plan:

> ***M3:*** *'Yes I know when I am becoming unwell. I have a plan of what to do and it works. It does work and if I start crying (lucky enough I haven't cried for a*

long time), I can ring the CMHT because that's when I am going into depression again. I know what to do and they will respond.'

The data supports the notion that both parents and children retained a heightened level of worry, and for children, watchfulness about what might happen if their parent became unwell again. One example of an innovative approach to involving parents and children in this process was the '*Message in a bottle'* scheme (co-produced by Barnardos with parents and children). This tool was designed to be used by mental health workers to help families reach a shared understanding and agreement about what should happen in a crisis and why. Taking part together in this process helped parents and children to regain some control and for professionals facilitating this process who witnessed the immediate relief families experienced, this led to increased professional confidence and self-efficacy:

C10b: *'....and I know message in a bottle that's really helped. Because if my mum is really ill and she has a seizure or something the ambulance will just come in and they can go to the fridge door and see the message in the bottle – then they will know what to do'.*

A mother and social worker talking about CAF meetings:

M7: *'It's very good, because people hear the same story and we have a meeting every three months and everyone one knows what everyone else should be doing. Everyone is all in the same room.'*

BarMan7: *'Bar7 [social worker] in collaboration with the CAMHS psychologist has been instrumental, particularly with her contact with CAMHS in bringing all of the agencies involved together and for the family this has meant that those professionals who were not communicating with each other are now doing so. Previously they would communicate through Mum and sometimes what Mum had to say resulted in agencies reacting to situations Mum described by instigating child protection concerns that when followed they would find these concerns were already being managed.'*

Parents talked about how, when problems at home became critical, they had sought out or been referred for parenting support, which included: help with anger management; help to control their children's behaviour other than by smacking; ways to improve their relationship with and 'bond' with their child; and help with specific and moderate to severe child behavioural, health or developmental problems. The help that was available was varied and included: peer support at parenting support groups; practical skills development; emotional support from a family support worker; and family therapy from CAMHS services. However, most of these interventions were short-term and the findings identify that when (short-term) parenting support ends and difficulties in the family persist, for example; poverty, fluctuations in mental health, poor housing – any improvement made as a result of these interventions deteriorated or disappeared altogether. Professionals in particular (including CSC professionals in the focus group) stated that in many cases once the CSC goal of achieving *child safety* was achieved i.e. immediate threats to safety diminished and there were no further incidences evoking concern, this, coupled with the demand on services, led to child protection plans being ended and cases closed; with the long-term consequences un-established or not addressed, and with no scheduled review to assess whether successful outcomes had been maintained.

Stepped-up intensive contact from *CMHT Crisis Intervention Teams* helped parents to avoid hospital admission and parents and children being separated. Regular and frequent visits allowed workers to see more of what was happening at home and as a consequence they more readily involved children by talking to them about their parents and asking them about how the family were coping. Frequent contact enabled parents and children to feel 'safer' and 'be' safer when parents were very unwell:

> ***CMHT7****: 'I made a referral to the Crisis Resolution Home Treatment Team because of an escalation in M7's self-harming behaviour. This has been very successful as it enables M7 and the family to have additional support at home when things are particularly difficult. The team are able to go in two or three times a day if necessary. The workers talk to the children to find out how they are coping and offer support. Being able to offer ongoing support, plus crisis*

intervention and therapeutic work has enabled the family to feel more confident that help is there when it is needed.'

For one family, the provision of a planned 'looked after' service for the child when the family was under stress, for example when the parent was in hospital, was a very valuable source of support as the child always went to the same foster carers who developed a positive relationship with both mother and child.

Family contributions to safety as success	**Number of respondents**
Total number of research respondents who talked about this theme	22 (44%)
Parents who talked about this theme	5 (41%)
Children who talked about this theme	8 (63%)
Professionals who talked about this theme	9 (36%)

There were clear and far reaching benefits for families who were supported by extended family members that knew them well and were willing to be there to help *in* and *out of crisis*. Adult partners/fathers, parents/grandparents, siblings/aunts and uncles and close friends helped families by identifying and monitoring early signs of deterioration in parental mental health and quickly mobilising support to prevent a crisis occurring or ameliorating the impact should one occur. '*Being there'*, knowing what is like at home when things are difficult and providing support to '*keep families going'* and '*keeping them safe'* promoted family resilience, including parental and child mental health and wellbeing. Unfortunately, few families benefitted consistently from this kind of support – see also *Contributions to success,* page 218.

1b. Wellbeing as success

The findings in this section are categorised and reported using the '*five ways to wellbeing'* a set of evidence based actions to improve personal wellbeing (Foresight, 2008).

Connecting with the people around you	Number of respondents
Total number of research respondents who talked about this theme	37(75%)
Parents who talked about this theme	10 (82%)
Children who talked about this theme	12 (92%)
Professionals who talked about this theme	15 (58%)

Five themes about *Connecting with the people around you* were identified in the data and they are: keeping the family together; improved mental health for adults and children; improved family relationships; and support networks.

Parents said '*keeping the family together'* in spite of extreme adversity, was the most successful thing that had happened for the family and their own most significant achievement. Preventing children going into local authority care had additional significance for parents who had spent some of their own childhood in care:

> ***M4:*** '*Bringing them all (four children) up together, which I've succeeded in, has been my main objective. I've got through it and they have never been into care.'*

When other aspects of parent's lives improved, parents felt that they were more available to their children and had more energy and emotional capacity to listen to their problems and try to help them. Improvements in mental health, making new friends, and getting essential housing repairs completed, were all cited as contributory factors to freeing up parents' capacity to support their children. Having 'quality' time for oneself was associated with keeping well, as was having time to spend with an adult partner:

> ***M1:*** *'Building Bridges offer trips in the summer holidays, like Chessington, the sea side, every week they have an outing somewhere different for the whole family. This is a success because I got to spend time with XXXX my partner because I spend enough time with the kids and we don't get out much together.'*

M1: *'I suppose I get a break on Tuesday from him (son) when he goes to the crèche. Not that I really need a break, but you do. I don't care what anyone says, if someone says do you want a full time nursery place and the government had the funding to do it – I don't know anyone who would say "Oh it's OK I would rather look after my son myself". The children benefit too, they interact with other kids and everything and I can do my own thing – I go to the walking group on Tuesdays now.'*

M12: *'Yes the trips have made a difference. I think just so he can get out and be with kids the same age and stuff. Just a break away from me.'*

Improved mental health for adults and children	**Number of respondents**
Total number of research respondents who talked about this theme	30 (6%)
Parents who talked about this theme	11 (91%)
Children who talked about this theme	6 (47%)
Professionals who talked about this theme	13 (52%)

Improvements in adult and child mental health were described as either primary examples of success, or contributions to success, by all participant groups. Children, professionals and parents identified links between improved mental health and parenting, because: parents became less withdrawn, irritable, angry or negative; more trusting of others including family members; their alcohol and drug misuse decreased; they were more emotionally available to their children and more able to undertake household tasks. As a consequence, children were less stressed and worried, less angry and more able to talk to their parents:

Bar7: *'I think for C7 she's more able now to say what she's worried about to her Mum.'*

Bar11: *'For C11 the change in M11 [improvement in Mum's mental health] means that she doesn't have to take on so much responsibility.'*

> ***CMHT11:*** *'The first few months of my visit M11 would open the door to me just in her night clothes because of how her mood was and how she was feeling. Now when I make an appointment I have to arrange my time around M11 which is good because she has so many things to do now. When I see her now her hair is done, she dresses well even if she isn't going anywhere, she is taking pride in herself and she is very welcoming. Before she would have little eye contact and only comment when spoken to. Even the level and tone of her voice has changed; she welcomes me with a hug. She smiles and she seems very changed so yes it is a very big plus on her mental health.'*

> ***CMHTMan3:*** *'Well I would hope that the fact that M3's mental health has been stable and that she is getting support means that the family feels more settled and that life perhaps is more back to normal, like it was before her mental health crisis, which I think is a result and that the family remains intact and that Mum is able to care for him.'*

Fewer hospital admissions and shorter admissions as a result of sustained mental health were also very important to children who did not want to be separated from their parents. A further consequence of improved parental mental health was that contact with extended family and friends was more likely to be resumed which was an important source of reassurance and comfort for children in particular:

> ***M1:*** *'Well my mental has got better, I haven't been in hospital, it has been the longest gap – I suppose that is better. I haven't been in hospital since I had him [youngest child)]'.*

Parental mental health improved noticeably when parenting responsibilities were significantly reduced or where parents had regular breaks from parenting in three families. For the first parent (M1), it happened when she met a new partner who shared the parenting role with her, for their son and her daughter from a previous relationship. For the second parent (M2), this took place after her children left home for university. M2 had been taking anti-psychotic medication for many years. She described (see below) how her mental health and quality of life improved significantly when her parenting responsibilities reduced and she felt able to stop medication with

the support of her community psychiatric nurse (CMHT2). For the third family, moving home to be nearer to the children's father and paternal grandparents meant that they were able to give mum (M3) much more child care support which reduced the impact of parenting on her mental health, allowing her more time for herself. The children enjoyed spending time with their dad and grandparents and they were also there to support mum:

> ***M1****: 'He (partner) helps with night feeds because I would have got ill if I didn't have enough sleep and I told him that. Because he said "well I have to work so I don't want to do any night feeds" and I said "well do you think when you are at work that women sit on the sofa watching telly?" When you have got a new born baby for the first few months it is hectic. So I woke him up basically every other feed and we took it in turns.'*

> ***M2:*** *'I would say the first 11years of this illness I slept my way through it, I got up at the right time, I set alarms, got up and cooked for the boys and then got them and to school and in their bed rooms again by 9 o'clock then I would fall back asleep on the chair in between times. My quality of life has improved as a direct result of stopping medication. And part of the reason I was able to stop taking it was because I don't have to carry out the day-to-day responsibility of being a mum looking after the two boys.....Yes I am more at ease with myself. I am not on any medications any more. I decided not to take it two years ago. I know the symptoms if I am not well. I know what to do and who to ring and whatever, it's quite under.'*

> ***M3:*** *'Yes, I have got my support network here and it is better here now than when I come. I had a good support network at XXXX but being nearer to family has made all the difference because there is somebody just around the corner that knows me as person. I have friends that know me but not properly know me and not properly know my illness.'*

Improved family relationships	Number of respondents
Total number of research respondents who talked about this theme	17 (34%)
Parents who talked about this theme	4 (33%)
Children who talked about this theme	5 (36%)
Professionals who talked about this theme	8 (33%)

Parents used the knowledge they gained through psycho-social interventions and parenting support to improve their understanding of mental illness and child development and make changes to their parenting behaviour. These changes led to a number of positive family outcomes including: improvements in children's behaviour and mental health; children reaching developmental targets (previously delayed), for example, speech and language; parents feeling less stressed and more confident; and improvements in the relationship between parents and their children, most notably the way they communicated and understood each other:

> ***Bar8:*** ***'****C8 was convinced his Mum was going to die and he has also got health problems that are ongoing. We have worked on these issues with C8 and now he knows his Mum is not going to die but he understands that she is not well.'*

> ***Bar10:*** ***'****There was a lot of work done by the previous worker XXXX particularly with mum around her relationship with C10a and to hear mum saying now "C10a and I are getting on really well" is something that we would never of heard maybe two years ago, so it is good to hear her acknowledging that and the difference it has made.'*

> ***M3****: 'I take them to the park now. It is only down the road. The park is not even far but I wasn't even taking them there to start with but now I take them and play with them a bit more. Before I had all the Play-doh and plaster and that but I wasn't using it because of the mess, but now I let them play with it, we did some plaster of Paris the other day, so I do let them make a mess*

because now I think to myself that they're only little and they are going to get bored.'

CSC3: *'Mother now has more of an understanding of the children's development and emotional needs, she's worked at building her relationship with her five year old son whom she felt she had not bonded with. M3 feels more able to sit and cuddle him and kiss him at bedtime. M3 is now beginning to take both children to the supermarket to shop. M3 is sitting with the boys at meal times... M3's now able to cope with the boys playing with toys and activities that make a mess. The children are now listening to M3 when out of the house and walk with her unless she says they can run a short way. M3 rarely smacks the children now as she's using other strategies to set boundaries.'*

BBPrac1*: 'M1 mentioned during her assessment that she had difficulties with her relationship with C1 and a lot of what she said was negative towards C1 "C1's lazy, C1's this or C1 is annoying her. Then it was more about "Can you sort out C?", I guess, rather than thinking it might be about parenting difficulties.... She's come a long way really in the last few months. She approached us and said 'I am having real difficulties because I don't know what is going on and I feel very angry toward C1'. We explored that and begun looking at 'attachment' issues, advising and supporting her to look at what is really going on with her and C1's relationship and her parenting. M1 has moved away from "it's C1 that is the problem" and now has some insight into what the possible reasons for the problems might be.'*

Different individuals from one family independently described how, when changes occurred in one mother's life, she became more confident and able to take charge in an adult relationship that resulted in positive changes for the whole family:

M10*: '.... I kicked him (ex husband) out about six years ago. And it's a bit of a coincidence that since then I have been getting more and more well, that's interesting isn't it.'*

C10a: *'.....I notice that since my Dad left, since they have separated she's [mum] doing much better because like in the past all they would do is argue and they were shouting, and screaming bad things'.*

C10b: *'I see my Dad and he is married now and I'm really glad for him. It's better for me, better for Mum, better for C10a, better for Dad because if he didn't get married; if he didn't meet his wife, he would be just still be living in a flat upset, but he is really happy now and he has a kitty, a nice ginger kitty called XXXX .'*

Regular opportunities for *respite* helped to decrease stress in the family and boosted family resilience – see also *Final outcomes – safety as success,* page 120 and *Intermediary outcomes – effectiveness as success page 152:*

Children were extremely loyal to their parents and were fiercely protective of them. This, and the positive attitude that most young carers adopted, helped children to accept their situation more readily, and, as a number of children said, '*just get on with it'.* Some children said that caring for their parent had made them mature more quickly and this had been useful in other areas of their lives and would help them in the future.

Support networks	**Number of respondents**
Total number of research respondents who talked about this theme	26 (53%)
Parents who talked about this theme	10 (82%)
Children who talked about this theme	8 (63%)
Professionals who talked about this theme	8 (33%)

Emotional and practical support provided by extended family members and friends that lived close by provided a crucial contribution to improving wellbeing for families when this was available – see also *Final outcomes – safety as success –family contributions to safe*ty on page 123. Renewing relationships with estranged family members became possible for some families when parental mental health had

improved, because: parents were more motivated; their feelings of guilt and shame about their circumstances had reduced; they felt more able to explain what had been happening for them; or they were less paranoid or depressed. Spending time with other family members and having fun together was central to what works for children and gave made parents feel more visible:

> ***C8:*** *'My Mum is a bit better, we all are, as we are really close to our family now like if we need any one to speak to my uncle is just around the corner and so is my aunty and my other aunty is just up the road. We didn't see much of them before. Sometimes I will just walk up and see them and talk for a while.'*

> ***Bar12:*** *'Now the family are less isolated and Mum now has contact with her own mother and other members of her family in Chester and with her two older sons and daughter who live quite nearby and C12 now has contact with his Dad and plans to go on holiday with his Dad and his new family.'*

Parents and children who had established a consistent trusting relationship with a professional emphasised the important contribution that these relationships had made to the way they experienced their lives. Parents and children also identified the contribution that they made themselves to enable these relationships to take place so successfully, which is not often discussed in the research literature. Parents and children spoke about the emotional risks they took allowing professionals into their lives, particularly when they had experienced difficulties in previous relationships with professionals and authority figures – see more about the benefits of therapeutic relationships in *Intermediary outcomes – effectiveness as success,* page 152.

Very few parents had established friendships, but for those that did, these relationships provided a significant source of comfort and reassurance. Some parents found it possible to derive positive adult contact and support from group activities in supported settings, e.g. drop ins, parenting groups, consultation groups at Barnardos Action with Young Carers or Lewisham Building Bridges projects. Making friends and having fun together was thought central to what works in the

lives for many of the young people interviewed, as was peer support for young carers:

> ***C10a:*** *'I actually have made new friends and I have got a best friend down the road and I feel more self confident now. This and probably Barnardos are two of the main things that have made a difference because I can go out and do things with people my own age and I enjoy it.'*

> ***C11:*** *'When my Mum came to tell me about Barnardos at first I wasn't really sure because then I was anxious and worried about what to think and everything, but when I came here it was better for me because at least I knew I wasn't alone and I knew that even in my situation other people have been through worse, so we kind of relate together.'*

> ***M10:*** *'They know they are not the only ones whose mum is not well – do you know what I mean?'*

Being active	**Number of respondents**
Total number of research respondents who talked about this theme	7 (14%)
Parents who talked about this theme	1 (8%)
Children who talked about this theme	2 (17%)
Professionals who talked about this theme	4 (16%)

Parents and children were encouraged to keep active and CMHTs and the voluntary sector agencies offered a number of incentives to families, including giving free gym and swimming passes and raising funds to get a walking machine for one parent (who was agoraphobic and not able to go out and had heart problems) and her daughter. Centre activities in the voluntary sector included trips out to the park, *Wii Fit* games and information about healthy eating. Children were more aware than their parents about the benefits of healthy eating and exercise. Community mental health services offered resources to support healthy living, for example, a walking

group and gardening, but without regular support and encouragement to take part these were difficult to sustain for most (but not all) parents:

> ***C6:*** *'The Personal Assistant is helping her (M6) to get healthy. He makes sure she gets to bed at the right time and gets up. He cooks healthy stuff for her and helps her when she sees the doctor. We now go to Asda and get a salad and she will now try these things and he tries to get her to walk about a bit more at home. You can see a difference in her which is good.'*

Take note	**Number of respondents**
Total number of research respondents who talked about this theme	29 (59%)
Parents who talked about this theme	10 (83%)
Children who talked about this theme	8 (63%)
Professionals who talked about this theme	11 (44%)

Singing in a choir, listening to music, going on a family outing, sitting in the garden, being taken to the country for a day out, taking up photography, were all examples that enabled parents and children to '*take note'* of the present. The voluntary sector agencies supported parents and children to enjoy themselves, have fun and take note by: providing financial support in the form of holiday grants and help with travel costs; supporting children to gain confidence travelling alone; organising and facilitating group activities for parents, children and the whole family. They also provided transport for parents *and* children so that parents could be the ones to take their children to and from these activities. These experiences provided respite from difficult situations, helped parents and children to make friends and meet new people, to experience new things and have shared family moments of happiness making them feel like a 'normal family':

> ***M6:*** *'C6 enjoys the trips at Barnardos and outings. Bar6 arranged for C6 to have a holiday but she didn't want to go at first. But the next night she was laughing on the phone to me. She is going away again this year. This makes*

me feel good as C6 is experiencing things I could not provide and I can see she is benefitting.'

M8: '*We have all been away together, Bar8 got the money for us to go on holiday, which is lovely. 'Last year we went to Blackpool and this year we're going to Pontin's in Wales so as a family it is great. I couldn't afford to do that, you know. C8 is dead excited.'*

CMHT11: *'In the summer holidays they were given money for transport and they went bowling as a family and when I went to see her afterwards she spent the whole visit talking about this, which is great because they all talk about what they got up to. How fantastic it was for the children to do that and for her to be there with them and do things as a whole family.'*

C12: *'The biggest success is probably Barnardos (Action with Young Carers) because I can go out and do things with other people the same age as me and I enjoy it.'*

Bar8: '*I got some money for them for a holiday grant to enable them to get away on a family holiday. To just get out Liverpool, away from what's going on for them.'*

Keep learning	**Number of respondents**
Total number of research respondents who talked about this theme	19 (38%)
Parents who talked about this theme	5 (41%)
Children who talked about this theme	2 (11%)
Professionals who talked about this theme	12 (48%)

Learning is closely intertwined with wellbeing for adults and children, and parents believed that if their children were doing well at school this must mean they had done

something right as a parent and that their difficulties had not affected their children too much and they drew comfort from this.

Professionals' emphasised that success should be understood in the context of previous experience and what might be a small step forward for one person could be a huge leap forward for someone else:

> ***Bar9:*** *'C9 has started a course and he is attending. Although it seems like small steps, these are massive ones because he has not been to school, college or hardly ever answered the door for a very long time. Now he is going to the course, travelling there by bus on his own so that is massive steps.'*

Being supported to reach one academic goal emerges as a motivator to go on to achieve further success for both parents and children:

> ***M1:*** *'Yes, I have started doing my Open University Degree which is a major thing which I have been scared to do for years.'*

> ***Bar12:*** *'I referred M12 to an education service and she has just completed an English course over the last twelve months and was awarded a diploma and is now going on to do level two, which is amazing given that when I first knew her she would never get changed out of her pyjamas and if she did have to go out shopping she would go out very early in the morning or late at night because there would be less people about and she would have to go with C12. She completed her course in 12 months and she is very excited about starting the next course.'*

Achieving a school placement that was a good match for a child's interests and aspirations, and one that adopted a proactive and sensitive approach to supporting children in the context of their family, was considered a major achievement by parents, children and professionals:

Bar10: *'School are heavily involved, both children are high achievers, mum fought really hard to get them into single sex schools, one of them is a church school and she had to fight really hard for this, with our support, to get the children into the school of her choice.'*

Bar10: *'He (C10b) has found his own niche I think, going to the right school for him is really positive and he has been able to develop his interests there and I think that if he had gone to the local comprehensive that things might have worked out quite differently for C10b. He is in a kind and supportive school environment.'*

Interestingly, some children who had to juggle high levels of caring responsibilities and school work repeatedly did well academically, regardless of what was happening at home. It was clear that school provided respite and a distraction from home for children. Children knew what to expect in the school environment and they could appear ‘like other children' or 'normal' if their friends were unaware of what was going on for them at home. The close support of a teacher or school mentor who knew about their situation at home was very beneficial for those children who had this resource, as was targeted support to facilitate the important transition between primary and secondary school.'

Bar8: *'He has recently been involved with our transitional years group, which helps the transition from primary to secondary school. Partly that is to do with learning to manage the travelling, where to get the bus there and the bus home, and all those little things that his Mum wouldn’t of been able to do and that it is made more difficult by C8’s learning difficulties.'*

Parents and children (but more so children) were supported to engage in a number of non-academic learning opportunities (by voluntary sector agencies and to a lesser extent CMHTs) including: first aid, learning to drive, art, singing, drama, and leadership skills courses. What was apparent, though, was the gap, often of many years, between offers of accessible and realistic opportunities that were of interest for parents to pursue.

Giving	Number of respondents
Total number of research respondents who talked about this theme	23 (46%)
Parents who talked about this theme	6 (50%)
Children who talked about this theme	4 (36%)
Professionals who talked about this theme	13 (52%)

Parents in particular were very interested and enthusiastic about '*giving something back'* to the agencies that supported them and to other families. They did not only want to receive, they wanted to contribute and share what they had learned. Where parents and young people were encouraged to participate in service planning, research and workforce development initiatives, particularly where they were able to see positive tangible outcomes associated with their involvement, this resulted in a strong sense of achievement and confirmation that they had something important and worthwhile to say. Similar outcomes were reported through taking part in peer support groups and church and community activities. Professionals agreed with parents that *participating* led to a reduction in isolation, improved confidence and self esteem and achieving in this way encouraged self-efficacy and the pursuance of further opportunities for success:

> ***M9:*** *'I am involved with the mental health consortium. I go to their meetings and to meetings about prevention at the primary care trust. Just yesterday I went to one meeting and I read out my story about being a service user and the services that help and what they need to do to make it happen. I have just been received so well, it is just wonderful and I feel like I can start to make a difference now.'*

In regard to *caring* as *giving* some young carers viewed their caring role and responsibilities as a positive contributory factor to their own personal development helping them to mature and increasing their capacity to cope with challenges in the future.

Summary

More than half of the parents, children and professionals interviewed associated *safety as success* with: good quality, inclusive crisis intervention and prevention planning processes; parenting support interventions, psycho-social casework aimed at promoting resilience; stepped up support during crisis e.g. Crisis Intervention Teams, and emergency respite care. The more parents and children were involved in care planning, the more their anxiety reduced in and out of crises. However, these outcomes tended to be short-term if intervention was short-term and family problems persisted. Fully involving families in crisis and contingency planning also increased professional confidence and self-efficacy. Assertive outreach and staying involved overtime and really getting to know the family made it possible to identify safety and safeguarding concerns and as a consequence families received help previously out of their reach. Support from extended family members (although rarer) provided a crucial element of maintaining safety and promoting wellbeing for parents and children.

The findings about *developmental success* highlight the important ripple effect that a *strengths*-based model of practice that incorporates a *systems perspective* (that attends to the needs and wishes of individuals if the context of their family and their community) had on promoting safety and positive mental health and wellbeing. The most talked about aspects of professional practice associated with developmental success were: having an understanding about the factors that can promote resilience in adults and children; knowing too the range of approaches that can help deliver these; and being open to offering support in un-traditional ways. There were also examples of services that aimed to intervene early to break down the cycle of impacts that can occur across the lifespan and generation, i.e. helping young people increase their chances for employment. Parental mental health improved significantly when parenting responsibilities were significantly reduced and both parental and child mental health improved by having regular opportunities for respite from parenting and for children respite from the exposure to parents symptoms and behaviours and young carer responsibilities.

Whilst some parents and children experienced relationship difficulties, there was still a strong commitment by all of the parents and children to each other. The care

given by young carers, parents' determination to keep the family together and the willingness of family members to engage with support, were thought by everyone involved to be equally as important as service and professional contributions to success. Interventions that: promote physical health, provide opportunities to have fun with peers and together as a family, and provide opportunities to learn new things, were all associated with promoting resilience and wellbeing for parents and children. Making new friends and having fun together was central to what works for children as was peer support for young carers. Learning is closely entwined with wellbeing for adults and children and being supported to reach one academic goal emerges as a motivator to go on to achieve further success. Children who were placed in school's that were a good match for a child's interests and proactively supported children in the context of their family were highly associated with a range of positive outcomes for children. Participating in service and practice development was important on a number of levels. There were a number of examples of positive service and practice changes that had been influenced by parents and children, particularly in Liverpool. Parents and children also benefitted from taking part as this increased their confidence and their belief that they had something important to say.

The sub-themes of *safety as success, developmental success* and *wellbeing as success* are then intimately connected in this study about parental mental health and child welfare. They are all as much about prevention, mental health promotion and promoting individual and family resilience as they are about intervening with additional support in times of crises and taking immediate action when safety is compromised.

INTERMEDIARY OUTCOMES OF SUCCESS (2)

Intermediary (process) outcomes are about impacts which parents, children and professionals associated with the final outcomes or changes (described in *Final outcomes* (1) above) and/or may assist in bringing final outcomes about. There are three sub-themes in this category of success which will now be discussed in turn and they are:

a. Satisfaction as success
b. Inclusion as success
c. Effectiveness as success.

2a. Satisfaction as success

This category of the findings about success relates to service user satisfaction. It casts the service user as consumer, as evaluator of the worth of the intervention. The findings about satisfaction as success are broken down into four sub-themes, each of which will now be discussed. They are: therapeutic relationships; co-ordinated and inclusive care and support; help to understand mental illness; and opportunities to have fun.

Therapeutic relationships	**Number of respondents**
Total number of research respondents who talked about this theme	37 (75%)
Parents who talked about this theme	11 (92%)
Children who talked about this theme	11 (92%)
Professionals who talked about this theme	15 (60%)

The majority of the parents said that achieving a mutually respectful trusting and established relationship with a named professional was one of the most positive things that had happened for them:

> ***M4:*** *'Yes it's made a big difference because I don't feel so isolated knowing that I got Bar4 there for me. Without Bar4 I would be lost.'*

> ***M6:*** ***'****XXXX (PA) – has been the biggest success. He is able to go away to his own house at the end of the day – so I don't feel such a burden on him. I love him. He spends five hours a day with me. My children still help but it has taken a lot of their caring responsibilities away.'*

> ***M9:*** *'Definitely getting a connection with the worker who is going to actually bond with us and do the things they should do and think about us, even if it's not a visit, it's a telephone call so you don't feel that nobody cares, so you feel you have contact. We love her to bits. She has been fantastic. God sent.'*

Children also valued the support of a close and trusting relationship where they could talk about their problems and their lives and receive help and reassurance. Young people said that the relationships they had with their social worker and learning mentor were amongst the most important things that had happened to them:

> ***C4:*** *'Well I would say my Mum's medication for one then the house then Bar4 (social worker) has helped a lot.'*

> ***C12:*** *'...yes, she [the learning mentor] was helpful because I could tell her my problems.'*

And a social worker about a child's school learning mentor:

> ***Bar12:*** *'The first example of success I think is the support available from the primary school and learning mentor and how well they worked with myself and the family and again that the head would allow things to be done over and above what was required and which I think other schools at the time would not do. Like knocking on M12s door and getting him dressed for school etc. although he did live quite close but even so.'*

See also *Final outcomes as success* page 202 and *Professional contributions to success* on page 218 for more about therapeutic relationships.

Co-ordinated and inclusive care and support	**Number of respondents**
Total number of research respondents who talked about this theme	27(55%)
Parents who talked about this theme	8 (66%)
Children who talked about this theme	3 (25%)
Professionals who talked about this theme	16 (64%)

Parents in particular were more than satisfied when services worked with them and their children in a truly co-ordinated and inclusive way. They described successes

that related to the quality of communication between different professionals, between professionals and family members, and the co-ordination of services at different stages of the care pathway for adults and children. Without exception, this satisfaction was based on previously difficult experiences where communication was poor and services did not work together well. There were a number of positive outcomes associated with improvements to integrated practice. Parents emphasised that when communication and care planning processes worked well, this considerably reduced the stress associated with parents having to play the part of co-ordinator themselves and having to repeat the same answers to the same questions to different professionals. Parents were much more aware of care management processes and interventions, through experience, than professionals gave them credit for, although they were not always able to name processes/interventions accurately or understand some of the *professional jargon (*see also *Final outcomes as success – working together* and *Inclusions as success,* pages 224). One mum talked about how adult mental health services were interested in the whole family (this family had no recourse to public funds) and persevered to find and co-ordinate the support the family needed:

> ***M11:*** *'The best thing the CMHT did was not medication or therapy it was the consultant contacting the family outreach service they have and getting the family support worker (based in the CMHT) CMHT11 to come to see me. She came face to face with my frustration and found Barnardos for me and that was another breakthrough because together they broke the cycle by working together to address the cause of the problem which is the most important thing. Even the surgery, the GP, I was going there for almost eight years and they could not actually help. If I had had the help that the CMHT and Barnardos gave me from the start of my condition our lives would have been a lot better.'*

The contribution of different professional perspectives to the CPA and CAF processes, and practice and professional supervision, were seen to be extremely helpful in supporting professionals to 'take risks' or 'work outside' of what they considered 'customary practice' to support parents in important decisions about their recovery and treatment:

CMHTMan2: *'I presented M2 once at the CMHT multi-disciplinary team meeting (the team had been discussing whether to discharge M2 to her GP for future follow up). We discussed whether M2 should remain under the CMHT on CPA providing a maintenance role, as she had requested. The discussion concluded that 'why change something that is working' and that even when you think for some people it would be good to discharge them for others it would not. So why try to fix things when there is nothing to fix? She has been doing well so why do we want to say for example 'she needs to get a job', when she says I am OK with how things are and she is happy.'*

BarMan7: *'I think if [instigating the CAF process] has helped mum to feel better understood, she now knows who everybody is and what their role is so she is clear about who she's talking to about what and I think she feels more positive about being a parent as a result, she feels much more supported as a parent and able to talk about some of the things that are of concern to her. She is confident enough now that people have got a good enough idea of things so anything new coming along will be communicated anyone and something will happen.'*

Help to understand mental illness	**Number of respondents**
Total number of research respondents who talked about this theme	23 (46%)
Parents who talked about this theme	8 (66%)
Children who talked about this theme	6 (50%)
Professionals who talked about this theme	9 (36%)

Parents, children and professionals emphasised the importance and satisfaction associated with interventions that helped them to gain a better understanding about mental illness and how it can affect parenting and child wellbeing. Psycho-social education interventions aimed at building confidence, understanding and improving relationships between different family members included: opportunities for parents and or their children to talk about mental illness and their concerns in a 'safe'

environment; peer support groups; CAMHS family therapy services; and access to mental health professionals who could provide expert information about specific mental health problems, treatments and side effects. See also *Effectiveness as success/psycho-social interventions,* page 157 and *Safety as success,* pages 120 and 202.

> ***M3:*** *'Yes, I think being with the XXXX (CMHT) has been good, having somebody to see once every two weeks. It's brought out my confidence a bit more. I understand about bipolar now, I understand the illness now.'*
>
> ***M11:*** *'..... she [C11– daughter] is just totally different. She understands now that it is not too bad being a young carer now that she understands why.'*
>
> ***C11: '****We didn't really get on, because I didn't really understand she was sick and I thought – why is she doing this to me, she must not like me – and now we get on more.'*
>
> ***BBPrac1:*** *'This time [birth of third child] because M1 has more insight and has the support of her partner she was able to cope much better. She went to hospital for just two weeks and did not get sectioned and her child was able to stay with her. That is very positive isn't it?'*

Opportunities to have fun, make friends and learn new things	**Number of respondents**
Total number of research respondents who talked about this theme	29 (59%)
Parents who talked about this theme	10 (83%)
Children who talked about this theme	8 (63%)
Professionals who talked about this theme	11 (44%)

Parents, children and professionals placed a great deal of importance on promoting resilience and individual and family wellbeing through enjoyment and having fun.

Parents identified a range of activities that they had taken part in where they and their children were able to relax and have fun, which in turn alleviated stress and helped them to feel like a '*normal family.'* Children liked taking part in activities with other young people which they felt helped to build their confidence. Parents were relieved when their children were offered opportunities that they would not otherwise have been able to provide. Parents also received encouragement and support to provide these opportunities themselves. One parent for example talked about how working with a *family support worker* (CSC) helped her to understand more about what her children needed from her, including playing with them and providing them with opportunities to have fun:

> ***C1:'*** *.....it's fun I like being with the other children that go. And last summer they [Building Bridges] took us to Chessington and we had an ice cream and pizza party.'*

> ***M3****: 'I take them to the park now. It's only down the road. The park is not even far but I wasn't even taking them there to start with but now I take them to the park and play with them a bit more'.*

> ***Bar11:*** *'...the ability to be a better parent has improved M11's feelings about herself. The opportunity to take her children on activities has made them more of a family. I think for the little children they feel more parented.'*

Parents also enjoyed and benefitted from spending time with their peers; for example attending a parents drop-in or a walking a group with adults who shared similar experiences.

2b. Inclusion as success

This section of the findings reports on three categories of inclusion as described by parents, children and professionals, which are: the inclusion of gaining service accessibility; the inclusion of meaningful participation; and organisational commitment to families.

The inclusion of gaining service accessibility	Number of respondents
Total number of research respondents who talked about this theme	16 (32%)
Parents who talked about this theme	7 (58%)
Children who talked about this theme	2 (17%)
Professionals who talked about this theme	7 (28%)

Professionals and organisations that are flexible and help parents and children to access and engage with services and resources that were beneficial but previously inaccessible, were identified as an example of 'success': Knowing about what sort of interventions can help families, what resources might be able to help in different situations, and being prepared to signpost parents and children to what can help – and supporting them to take up interventions – were all ways that parents and children felt that professionals had successfully helped them to access support that worked for them:

> ***M12:*** *'C12's primary school were really good. He used to have a learning mentor, she used to come out to see me and she used to go places with me as well, like C12's reviews and stuff, she would come with Bar12'.*

> ***M10:*** *'Plus their schools are excellent and are in contact with Barnardos Bar10 used to go and see them at their school. And the head of year keep in touch with me, to see how we are as a family and they would ring up and ask me how I am and if I'm keeping well and how I am getting on, it is really nice . You come as a package.'*

One mum explained how her social worker supported her by going to meetings with and helping her to communicate with her psychiatrist who she had previously refused to see:

> ***M4:*** *'Bar4 explains for you what your problems are.'*

Professionals who worked in agencies or teams where they were supported and allowed to spend the time needed to carry out assertive outreach and establish

relationships with families who had previously been difficult to engage, described this as the most important example of success for some families – see also *Final outcomes – safety as success,* page 120:

> ***Bar12:*** *'I think it took six to 12 months to engage M12 properly in services. Yet I knew it was important to persevere as I knew that if we could get her to engage there would be improvement. Being flexible was part of it, we came to her and got others to come to her as she couldn't get out of the house and we allowed her friend to be there, which were all ways of supporting her to be involved.'*

> ***BarMan4:*** *'There is something about the impact of the perseverance around engagement, knowing there is a young carer there and the kind of obstacles that exist for them to become involved, and knowing what to do to try and overcome these obstacles with the family. So I know for example the relationship that Bar4 has with mum (M4) has taken a long, long time to develop. And the benefit for the whole family is actually, you know, that there are people out there who will persevere and who will stay in there, regardless or maybe not regardless but despite you making your best efforts to kind of not engage with them, if that makes sense.'*

Similarly, when an individual or family were discharged from a service, they effectively stepped off of the care pathway at that point. Then when a problem occurred in the future the whole process had to start again in terms of finding someone to help, getting a referral, etc. Services or professionals who knew the family well, based on previous contact, and who offered to be the first point of contact in the future, enabled families to get help quickly, before problems become too entrenched, by signposting them to the right help and supporting the referral:

> ***BarMan9:*** *'It has been important for this family to have been able to come back to us and say, you are probably not the right service but actually because we know you, can you just point us in the right direction. All the time we get young people (*young carers*) who are in their 20s coming back to us,*

saying, 'I have come back because I don't know who else to go to and I don't know who to ask'.'

See also *Professional contributions to success,* page 218 for more about the value placed on signposting and flexible support to engage people with services that can help.

The inclusion of gaining meaningful participation	**Number of respondents**
Total number of research respondents who talked about this theme	25 (50%)
Parents who talked about this theme	10 (84%)
Children who talked about this theme	6 (50%)
Professionals who talked about this theme	9 (36%)

Parents and children had varying degrees of awareness about how adult and children's services' assessment and care planning processes worked. However there were many examples of how when these processes worked well and were truly participative, they were experienced by parents, children and professionals as examples of success – see also *Satisfaction as success* page 207.

A mother talking about a multi-agency *Children's Assessment Framework* (CAF) meeting:

> ***M7**: 'It's very good, because people hear the same story and we then have a meeting every three months and everyone one knows what everyone else should be doing. Everyone is all in the same room.'*

The findings about crisis and contingency planning tools (as described in *Safety as success,* page 120) also highlight a correlation between the amount of involvement children had in this care planning process (mostly for their parent) and their levels of anxiety *in and out of crisis;* i.e. the more they were involved the more their anxiety

decreased. The inclusion of parents and children in this way optimised outcomes that were not just about minimising risk and dealing with immediate safety, but also about prevention and mental health promotion:

> ***C10b:'*** *....and like I know 'message in a bottle' that's really helped. Because like the ambulance if my mum is really ill and she had a seizure they just come in and they can go to the fridge door and see the message in the bottle and they know what to do.'*

> ***M7:*** *'She (child) still does a lot, but a lot less than before now that some things have been put in place. For example, have you heard about 'a message in the bottle?' This has taken a hell of a pressure off of C7 I think, she doesn't worry about me so much.'*

Professionals described how parents and young people were visibly empowered when they were able to lead their own care planning process or formally complain about services or incidents that they were unhappy with, even when these experiences were in the past:

> ***Bar10:*** *'C10a had a lot of anger as she was really angry about her experience in care, for example, that she held with her for a long, long time and again part of that being able to write it down and make a complaint and supporting her to do that benefitted her enormously.'*

A further example is the employment of a *personal assistant* to support *M6* using a *direct payment* (which are notoriously under-utilised in mental health care) made the most difference for one family. Everyone involved in this case study had examples of positive outcomes resulting from this appointment:

> ***M6: '****XXXX (personal assistant) – has been the biggest success. He is able to go away to his own house at the end of the day – so I don't feel such a burden on him. I love him. He spends five hours a day with me. My children still help but it has taken a lot of their caring responsibilities away.'*

C6: *'I think the biggest improvement has been getting a PA. My Mum has even been out for a day with the PA and she hasn't been out for a very long time.'*

CMHT2: *'M2 she won her council case that has taken up the last five years, but she persevered and this positive result has really boosted her confidence and self esteem.'*

BarMan6: *'I would say that the most significant change has been the care support package and direct payment for mum as she's been able to employ her own personal assistant. For C6 to hand over a lot of caring responsibilities and receive support for herself it means doing the things that she really enjoys and this is really, really important for mum as well.'*

Parents and children spoke positively about their experiences of participating in workforce and service development forums and how being able '*to give something back'* to the services that had supported them was very important to them – see also *Wellbeing as success – giving,* page 207 for more on the dual outcomes of participation. Talking about their lives proved to be a useful exercise in itself and was something that a number of parents and some of the older children mentioned at the end of their research interviews. For some who found getting out of the house difficult, getting involved improved their motivation and helped to reduce their isolation:

M7: *'It is helpful just like coming to see you [interviewer] because it gets me out of the house and doing things myself and I suppose getting out of the house is a big achievement for me, so.....'*

M2: *'No, I am not involved [mental health trust advisory board] any more, I got bored with it at the end, I did all I could and obviously some of the things I said they have implemented and that makes me feel good.'*

Bar5: ***'****C5 has spoken to audiences about how completing a carers assessment [at Barnardos] has changed her, because she went from having*

no support to having a number of people involved with her. She hadn't done any written work since she stopped going to school a couple of years earlier and having now written something and presented it to people who wanted to hear about what she had to say and her experiences really boosted her confidence' (See Appendix 6 for a copy of what C5 had to tell her audience).

Organisation commitment to families	**Number of respondents**
Total number of research respondents who talked about this theme	29 (59)
Parents who talked about this theme	9 (75%)
Children who talked about this theme	11 (92%)
Professionals who talked about this theme	9 (36%)

Professionals from all agencies were very clear that positive changes had been made in this area of practice and that everyone was more aware that they had to think not just about the individuals that were their primary client; they also needed to 'think family'. Statutory agencies had made changes to their statutory assessment framework questions for example to include attention to the needs of parents and children. Both research sites had different inter-agency protocols that aimed to improve collaborative working for the benefit of families. The effectiveness of assessment tools and protocols though depended more on practitioners and managers commitment to their use than the quality of their content it seemed. All of the professionals taking part said that professional supervision that allowed them to reflect on their practice and gain further perspectives was instrumental in enabling them to contribute successfully on behalf of families. There were many examples of training courses that managers encouraged staff to take part in that had been helpful, and courses were said to be particularly helpful when different disciplines trained together and where parents and children contributed to the training. The introduction and mandate to use different clinical tools (*HONOS* and *Lunsers*) helped those clinicians who were committed to using them to do the job of monitoring mental health and side effects more effectively with parents.

In Liverpool, families and professionals said that they were aware of national and local developments that were about improving the lives of families affected by parental mental health. A number of parents, children and professionals had been actively involved in these developments and talked very positively about this during interview. Whilst Lewisham was also involved in local development work of this kind, families and professionals seemed less aware of this; with only two professionals being aware that there was new national guidance (which they had taken part in the development of) and that there was '*something going on locally'* but they were not sure what. In Liverpool, the improvement work was overseen by a group of committed senior managers (directors, chief executives, etc) from health and social care agencies in adult and children's services. In Lewisham, the group overseeing the work were committed service managers from most of the same agencies in Liverpool. It was clear, though, that the sign up and commitment of managers from the top of organisations in Liverpool helped to progress work faster and embed changes into everyday practice more effectively.

Barnardos Action with Young Carers and Lewisham Building Bridges staff were able to engage families and achieve good working relationships with families that statutory agencies had previously found hard to assist. This was not just because of the stigma families associated with statutory services, but because these agencies were flexible and allowed the time needed for professionals to engage with families at the families own pace, and they stayed involved for longer periods of time. Similarly, schools that adopted a proactive and sensitive approach to supporting children in the context of their families were considered a source of strength by all participant groups, and conversely a source of stress for the family when schools did not understand and things went wrong.

1c. Effectiveness as success

Effectiveness as success is about interventions and service models positively evaluated by parents, children and professionals as examples of what had *worked* for them.

Interventions designed to increase resilience – applying a strengths and resilience-led perspective in professional practice helped professionals to engender optimism

and commitment in the family members and professionals that they collaborated with. Professionals supported parents and children to build individual and family resilience by encouraging them to take risks (e.g. meeting new people, going out of the house, returning to school etc.), congratulating them on their successes and helping them to achieve further success by applying what they had learned to other situations:

> ***Bar11:*** *'I got M11 to apply for a job on the mental health consortium which is a group that works with people that have mental illness and that is made up of service users. I thought that would be brilliant for M11. She got the post and is doing well with it and enjoying it. It is not a paid post it is voluntary. It is quite an academic post and it plays to her strengths and that is why I got her to apply for it.'*

Voluntary sector professionals in particular helped to provide the support and encouragement that children needed when their parents were not able to, for example; communicating with school, supporting a young person in a new job, helping a child deal with bullying, encouraging and providing a space for study during exam times. There were a number of significant outcomes for parents and children as a result of this professional approach, including, for one young person, getting a job and staying employed against all of the odds: Helping young people all of whom live in families where one or both parents were long-term unemployed to explore what they wanted to do with their lives was a prominent goal and example of success:

> ***BarMan4:*** *'I can remember C4 when he first became involved in the project. He swore a lot, he was quite insulting, didn't kind of relate very well to other young people. So part of the work that Bar4 has done has been to think about what kind of opportunities would support C4 to develop, so taking part in the Tall Ships programme for example. C4 didn't attend school very often, wasn't interested in education, and now he has got himself a job and seeing that kind of shift and change from this young man who was on the verge of criminal or anti-social behaviour to make really positive choices is fantastic.'*

Perhaps the most important contribution by professionals here was having an understanding of the factors that can promote resilience and that adults and children can make favourable progress in unfavourable circumstances. Knowing too the range of approaches that can help to deliver a '*strengths-based'* model of practice and being open to offering support in un traditional ways, was crucial to maximising *children's resilience, family resilience* and parents' *Mental Health Recovery,* for example*:* helping families to gain an understanding of mental illness; supporting a mother to stop taking medication by remaining involved; increasing self esteem and self-efficacy by encouraging and supporting a parent to apply for a *Direct Payment* or involving parents and children more fully in CPA contingency and crisis prevention plans.

Attempts to intervene early to prevent the cycle of impacts occurring between parents and children across the lifespan (childhood to adulthood) and across generations was also apparent; e.g. identifying, assessing and supporting young carers, supporting families through the transition from primary to secondary school and helping children to understand that they were not responsible for their parent's difficulties.

Medication – All of the parents interviewed had been taking psychiatric drugs of one kind or another for many years. Only one mother was medication free at the time of interview. Children and professionals believed compliance with psychiatric medication was a crucial contributory factor to improved parental mental health. However, whilst parents acknowledged that medication might have a role to play, they did not attribute anything like the same amount of significance to this as did their children or the professionals supporting them:

> ***M7:*** ***'****Well I said no [medication] doesn't work, but they (mental health professionals) said it does. I suppose it did help in a way, it settled me for a little bit, changed my mood a little bit, but it didn't make it go away.'*

Prescribing and taking psychiatric medication was not always straight forward, and as some parents experienced, there could be a certain amount of 'experimentation'

before optimum treatment levels could be established, which was disillusioning for some. Parents were disappointed that medication could not do more to alleviate their difficulties leaving some parents feeling pessimistic about their future. However, when mental health professionals and parents worked determinedly together to measure what treatment worked best, including addressing any side effects, better outcomes were achieved, that is: a therapeutic level was attained and symptoms improved; parents were less troubled by intrusive side effects and as a result stayed on medication for longer period of time; and their mental health was stabilised. Community Psychiatric Nurses (from one CMHT) said that regular and systematic use of standardised measurement tools helped them to work together with parents to monitor progress and find the best treatment options. The tools used were the *Health of the Nation Outcome Scale* (HONOS) (Royal College of Psychiatrists) which measures the health and social functioning of people with severe mental illness; and the *Lunsers* scale (Liverpool University) which is designed to monitor medication-induced side effects related to neuroleptic or anti-psychotic medications:

> ***Bar12:*** *'Changes in her medication obviously helped. Because you know quite soon after the new medication kicked in there was changes. Prior to the change she lived on tea, coffee and cigarettes but that all changed. She was anti some of the medication previously because of some of the side effects but now she can reflect on where she was two years ago and see the difference and acknowledge that medication is part and parcel of the change.'*
>
> ***CMHT3:*** *'Stabilising M3's mental health and making sure her medication is right and her side effects controlled [this Mum had experienced particularly nasty side effects previously] so that she continues taking medication and doesn't break down and relapse is an important example of what has worked.'*
>
> ***CMHT3:*** *'Getting on the right kind of medication has made a difference, it still matters as we still haven't quite got it right because we have gone from having her on medication and she reduced it drastically to such a point that it was below a therapeutic level. But it is now at a level where it is working and she can see that. So I think the whole discussion about medication has been*

a positive thing. We both have a better understanding about what works and doesn't work for M3.'

Children, even at a young age, were aware that their parents took medication and worried about the consequences should their parent stop. Some collected, administered, monitored and encouraged their parents to take medication. Children were able to describe very clearly the differences in their parents' behaviour when they were taking medication and when they were not:

C4: *'Well now she is on medication for it, it helps her stay calm and relaxed and all that, there's a big difference. She has been good on medication for about three or four years.'*

C9b: *'Medication helps, yes...because it all depends on the medication. If she stops and doesn't take it she will go down, yes.'*

Children were also aware that medication could not fix everything or be as effective when their parents were experiencing a lot of difficulties:

C12: '*No, she didn't always have medication and she had to cope at one point without it and then the doctor got her on it and it was alright at first. But because of the situation with our old house (it was falling down and very damp) the stress was getting higher and higher and she was getting more depressed. And then she lost her brother and that made her worse and then they had to up the dose and she still wasn't well, then when they moved her into our new house it got better.'*

Parents and some professionals acknowledged that stopping treatment can lead to improvements in health and wellbeing too and that support can be offered in different ways – see also *Final outcomes – improvement in mental health,* page 205**.**

Counselling – having someone to talk to who would listen and not judge them or their circumstances was extremely important for parents and children, and this did not necessarily have to be formal counselling or therapy. For example, children

found having the same person at school to talk to who knew about their difficulties at home made a great deal of difference for them and this person was often a teacher or a school learning mentor. Some parents and children had received counselling and some had taken part in family therapy. Parents on the whole said that they had benefitted from counselling and some were considering having more to help them with specific issues including: attachment issues; parenting problems; anger issues and the impact of early abuse and adult violence. But like medication, they had hoped it would help more than it did:

> ***M7: '****My eldest daughter was referred for counselling. It helped a hell of a lot, yes.....She was having emotional problems, and she just needed to sound off to somebody rather than me which is better.'*

Professionals described how children worry about their parents and what is going to happen to them in and out of crisis situations, and how these anxieties are magnified when parents confide in their children. Providing opportunities for parents to discuss their worries with other adults (at a women's or parenting group, with a trusted professional) was as important as providing respite for children in these situations.

Psycho-social education – help to improve parents' and children's understanding about mental illness and child development was available from CMHTs (mostly for parents and sometimes for children) and the voluntary sector agencies taking part (for parents, children and whole family). Reaching a shared family understanding of mental illness was seen as an important breakthrough for many of the families interviewed. On the whole, gaining a better understanding about what is happening and why led to a reduction in a range of stressors. Children believed gaining a better understanding about what was going on with their parent prevented deterioration in their own mental health, because they stopped blaming themselves so much for what was happening. Speaking to professionals who knew their parent and had seen their parent when they were very unwell was particularly helpful, as was speaking to other children with similar experiences. These interventions reassured children that what was happening was not their fault, and in some cases helped to improve their relationship with their parent.

***C9a**: 'Being helped to merely get an understanding about what mental health is and that it wasn't our fault is really important and the constant reassurance we got here [Barnardos] really was so important. I think that's what most kids need really because to know that you're not a bad kid and it's not you and everything else, yeah.'*

***C11:** 'We didn't really get on, because I didn't really understand she was sick and I thought why is she's doing all this to me, she must not like me and now we get on more.'*

***Bar12:** 'C12 has attended a lot of the groups here and through that he has gained more of an understanding about mental health. C12's idea used to be that Mum's mental health problems were other people's fault and that they were responsible for how his mother was.'*

Parents felt relieved when it was explained that what had been happening to them was an 'illness' and 'not their fault' and for some, with support, this made it easier for them to explain to their children:

***M9 '**...so basically then when I did come out of the hospital it was a good starting point for me, a great relief to know that how I was, was because of mental illness, it wasn't my fault you know and anyway with Barnardos support you know I could explain to the kids a little bit more.'*

***M3:** 'at least I know what's wrong with me now and it's not the case of having a funny turn, there's an illness, there is a word for why I am feeling the way I am.....being with the XXXX (CMHT) has been good, having somebody to see once every two weeks. It's brought out my confidence a bit more. I understand about bipolar now, I understand the illness now...'*

It was clear though that being given a diagnosis of mental illness resulted in a belief for some parents and children that parents were not responsible for their actions including problematic behaviour that was not attributable to symptoms of mental ill health, or beyond parents' control. Professionals also appeared to have a high

tolerance for some parental behaviour, explaining it away by attributing it to parental mental illness, or the very difficult circumstances that parents experienced (this is discussed in *Barriers to success,* page 220).

Support for young carers – providing reassurance and helping children to understand what is happening to their parent; reducing children's caring responsibilities; and providing regular opportunities for children to have fun with other young carers, were the three most cited examples of direct interventions that helped to improve the lives of young carers from the perspectives of parents, children and professionals.

> ***C6:*** *'Yes, because of Mum's personal assistant, I can go out more because before I couldn't go out much, because there was such a lot of stuff to do in a day. I used to get fed up and just you know stressed in my head and everything. I feel better in myself now, yes less stressed now.'*

> ***M7:*** *'She went [on holiday/respite break for young carers] last year and she really enjoyed it and it's nice for me because I knew she was safe and she was enjoying that.'*

Similarly, approaches that helped families and professionals gain a shared understanding of the difficulties, stressors, protective factors and the early warning signs of deteriorating parental mental health, helped them to reach an informed agreement about what was needed to prevent or intervene early in a crisis. This was empowering for parents and children, increasing their self-efficacy and feelings of wellbeing. A further example was taking part in a young carer's assessment which helped to validate and contextualise one young person's experiences – see Appendix 6 – for her C5's account of how taking part in a young carer's assessment helped her.

Social care support – where people lived, the condition of their accommodation, and how they felt about where they lived, was a significant topic of discussion. Getting essential repairs completed or moving from poor housing or hostile environments to housing of a better standard or to a more supportive community was very important and increased both parents and children's resilience in a number of ways. Children

in particular gained comfort, status and felt less stigmatised when they lived in safer, more comfortable surroundings that were near to their extended family and friends:

> ***M12:*** *'Well, it was really damp in the old flat and C12 didn't have his own room and we were sharing the same bed [mother and son] and stuff and now at least in the new place we got our own bedrooms so it has improved a lot.'*
>
> ***C12: '****A big improvement is our new house because it is better and it's not damp.'*
>
> ***M8: '****We had some trouble when my son was racially attacked and we've been through hell for about two years as we've been getting harassed. And then when we were offered this place I just took it to get out of a horrendous situation and keep the boys safe. The area is better but the house is not good.'.*
>
> ***C8: '****Well its better being in a new house because around our old house that area is racist and because we are black we got chased there, got called names, we got beat up, got a black eye and all that. We are happier now because nothing happens now. So moving has made a lot of difference.'*
>
> ***BarMan6:*** *'I would say that the most significant change has been the care support package and direct payment for mum as she's been able to employ her personal assistant.'*

Helping young people, all of whom live in families where one or both parents were long-term unemployed, to explore what they wanted to do with their lives was a prominent goal and example of success in Barnardos Action with Young Carers Project – see *Final outcomes, Developmental success,* page 138. Another way of improving employment prospects was professionals supporting parents to get involved in advocacy and advisory roles on a voluntary basis that played to the parents' strengths and skills they had prior to their mental health problems:

> ***Bar11:*** *'I got M11 to apply for a job on the mental health consortium which is a group that works with people that have mental illness and that is made up of service users. I thought that would be brilliant for M11. She got the post and is doing well with it and enjoying it. It is not a paid post it is voluntary. It is quite an academic post and it plays to her strengths and that is why. I got her to apply for it.'*

Service models associated with success – parents and children found the community-based services offered by Barnardos Action with Young Carers and Lewisham Building Bridges preferable to statutory service delivery models. Seeing families through or helping them to manage their difficulties takes time, particularly if their problems are complex, entrenched and longstanding. This was identified as an important contributory factor in the success of the Barnardos Action with Young Carers service model (by parents, children and professionals), i.e. the agency and workers were there (offering fluctuating levels of support according to need) for the long haul, through the good and the difficult times. In this project and Building Bridges, family members got to know all of the staff and the staff got to know them, they also came into contact with other parents and children who shared similar experiences. These community-based services enabled parents and children to experience being part of a community that cared about them. They felt less stigmatised when accessing these services and as a consequence more likely to access help when they needed it. Parents and some older children said that sometimes they avoided contact (for example, when parents were unwell or when they felt better and did not feel they needed support) but the key worker from Barnardos kept in contact from time to time, to check that they were OK. Being '*kept in mind'* in this way helped parents and children feel '*cared about'* and 'safe'. As a result of the trust that parents and children built with these projects and the individuals working there, they were more empowered to take positive risks to try and make things better in the knowledge that reliable support would be there whatever the outcome.

Parents and children did receive a range of practical and psycho-social support from Barnardos Action with Young Carers and Lewisham Building Bridges projects. Where parents and children had good relationships with statutory services they said

that again they benefitted from the practical and emotional support that the professionals from these agencies had to offer. They were, however, unanimously agreed that these professionals were too busy and did not have enough time to spend with them.

Summary

The establishment of a therapeutic relationship was extremely important because of how it made parents and children feel about themselves and their lives and because these relationships were often the gateway to other successes. Co-ordinated and inclusive care was important for those parents who experienced it, not least because their previous experience had been that services were hard to navigate and very disconnected. Help to understand mental illness was also a conduit to gaining the right kind of help. The more that families and professionals understood individual and family circumstances, the more able they were to access support that worked. Parents and children loved to have fun and respite from their difficulties. Having fun also meant contact with other people and new situations and helped individuals and families to learn and build resilience.

The data identifies social inclusion activity that supported people to access services previously out of their reach. Signposting and actively supporting people to take up services improved take up and engagement in services. Promoting and supporting user participation, and taking part (service users) in service and practice development resulted in changes and additions to services that were based on what had 'worked' for families. Professional practice was best supported when organisations allowed and encouraged professionals to go at the pace of the family; to be flexible and stay involved for the long-term if needed (which was the case for all of the case study families). Regular professional supervision which allowed practitioners to reflect on their practice; access to training and development opportunities; and learning from families, peer professionals and other disciplines were all ways that their organisations helped them to do their jobs most successfully.

The same range of biological, psychological and social models of intervention, delivered in different combinations, were highlighted by all participant groups as being effective. Being able to benefit from any intervention was dependent on: who was recommending or delivering the intervention, what else was happening for the

family at the time of the intervention, what other interventions were happening concurrently, and the timeliness, timing and duration of the intervention.

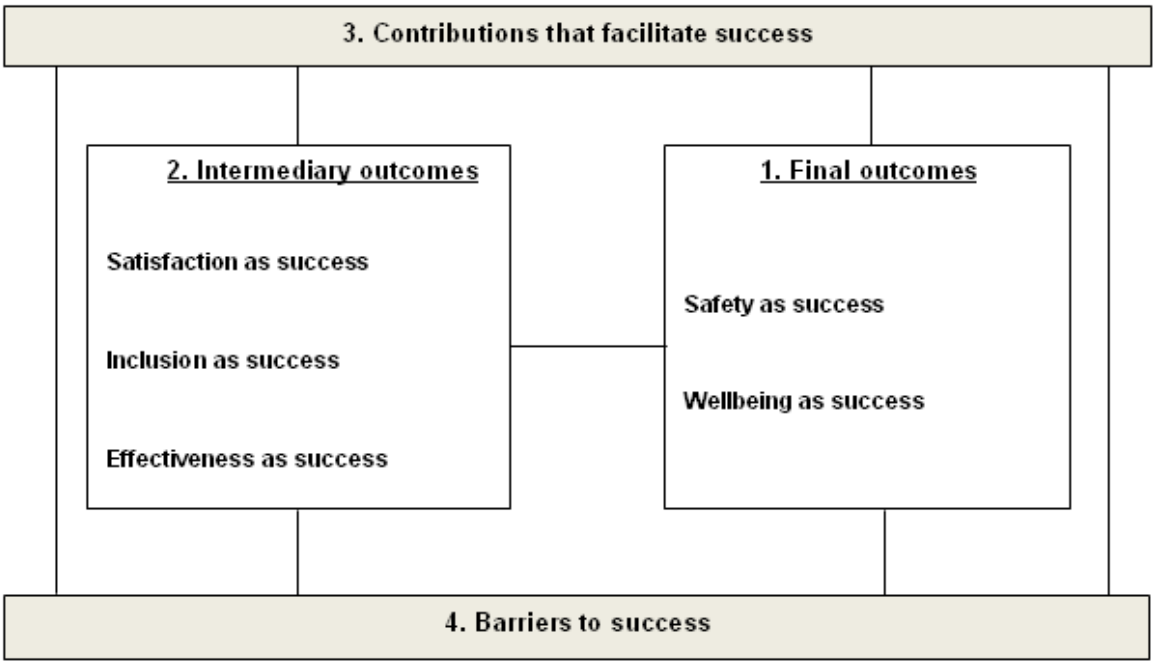
The next chapter sets out the third and fourth elements of success illustrated in Diagram 3, which are *Contributions that facilitate success* (3) and *Barriers to success (4).*

CHAPTER 8: FINDINGS (2)

INTRODUCTION

This chapter sets out the findings relating to: *Contributions that facilitate success* (3) and *Barriers to success* (4) (see Diagram 3). The chapter concludes with a summary of the findings from the file reviews and focus groups related to the findings from the interviews with parents, children and professionals.

Diagram 3 - Elements of success



The findings will now be discussed in numerical order as they appear in Diagram 3.

CONTRIBUTIONS THAT FACILITATE SUCCESS (3)

Parents, children and professionals were asked to identify their contribution to the successful situations they had described. They were also asked about who else had contributed. Each of data themes are preceded with a table that illustrates whether there was consensus or differences of opinion about different stakeholder contributions to success. The left hand column lists the type of contribution and the ticked areas in the columns to the right indicate which of the stakeholder groups said what.

Different stakeholders perceptions of parents' contributions to success			
	Parents	**Children**	**Professionals**
Persevering and being determined to make things better	√		√
Willingness to work in partnership with professionals and engage in services			√
Taking medication and staying well		√	
Reflecting, learning and putting learning into practice	√		√
Sharing what works for the benefit of other families	√		√

Persevering and being determined to make things better – professionals agreed with parents that there was a direct correlation between a parent's perseverance and determination to make things better and many of the successful situations that families experienced. Parents talked about times when they wanted their lives to end and how this was only prevented by thinking about their children and not wanting them to be left alone. Taking part and doing things, even when they were difficult, in the hope that they would make things better for themselves and their family was something that parents repeatedly did, even when it was at great cost to themselves:

> ***M7:*** *'I can be determined to get things right for my children, I wish I could be as determined for me.'*

> ***Bar7****: 'She went through a couple of really bad crises when she was working with her psychologist which destroyed her emotionally, as work like that often*

does. She is engaging with the 'working together work' with CAMHS, even though it's not that easy to sit in the room with all your kids there and a couple of professionals commenting on what you should and shouldn't be saying to them [children]. That's not an easy thing to do but she does it anyway. Even when her mood is low she still manages to try and she is fiercely loyal to her children.'

M2 talked about how fighting to get the council to fund essential repairs to her home took years, but her determination paid off, winning her the respect of her family and the professionals working with her. Her mental health improved as a consequence of this and she proudly showed me the home improvements she had made when I visited her home to interview her:

CMHT2: *'M2 won her council case that has taken up the last five years, but she persevered and this positive result has really boosted her confidence and self esteem.'*

Parents allowed and supported their children to take advantage of support when it was offered. Some parents felt guilty that they could not provide the support themselves, but did not allow this to get in the way of their children taking part. Parents who were willing to work in partnership with professionals, and who were able to reflect on their mental health problems and other aspects of their lives – including their parenting and the relationship they had with their children – used newly acquired insights and knowledge to: more successfully lead their own care; employ self help strategies; improve their relationships with their children and other family members; and know what kind of help their children might need and how to get it:

M3*: 'Me and XXX [ex-partner] talk even more now and I can take criticism and understand what he's trying to say and stuff like that. And through talking to him, because he has mental health in his family, I've found he understands how I am feeling. I was bottling it all up before and talking has improved my relationship with him.'*

M2: *'That's what doctors found really weird with me, as well as some mad things coming out of my mouth there was also sensible things. And I refuse to come off CPA. They think I am alright to look after myself but I like to know that there is a safety net there.'*

Parents were also very willing to share what they had learned from their experiences for the benefit of others, by contributing at conferences, policy and planning committees and at professional training events.

The majority of parents had little or no child care support so were caring for their children alone, and the effort needed to keep going for their children left little resources for parents to attend to their own needs. Lack of attention to their own needs and the impact of parenting on their mental health meant that positive outcomes for themselves were less apparent. This will be discussed again in *Barriers to success* at the end of this chapter (page 220).

Taking medication and staying well – the only thing that children had to say about what their parents contributed to making things better was to '*keep taking their medication*' as this helped to keep them well and ultimately resulted in a happier home. The links between mental health and physical health and the adverse affects of some treatments were obvious to parents. A few parents took steps to counteract these impacts by exercising to keep fit and making time to have a break to do things that they enjoyed or helped them to relax.

Different stakeholders perceptions of children's contributions to success			
	Parents	**Children**	**Professionals**
Having a positive outlook and striving to do well		√	√
Doing well at school	√	√	√
Getting a job	√	√	√
Being a young carer – caring for parents and siblings	√	√	√
Children looking after their own health and wellbeing		√	
Children sharing their knowledge and experience about what works		√	√

Having a positive outlook and striving to do well – children and professionals believed that the way that children thought about their lives had important consequences for the ways that things turned out for them. Children, who, with help were able to maintain a positive outlook and spent time thinking positively about their future, were thought to be more resilient:

> ***C11**: 'I still do the housework, shopping and stuff, I'm OK being a young carer [for M11] and I'm OK about looking after my brother and sister. I'm OK because I try and stay patient, I try to understand and although it might feel things are bad sometimes I just think that some good will come out of it because the things I am going through now might help me in later life... I think I have grown up more mature and responsible because of the things that I have done.'*

Striving to do well at school and having goals for the future provided an important focus for children. This was something highlighted by children, parents and professionals. Pursuing personal and academic goals gave children a sense of purpose and belief that things can be different. Children responded to positive feedback and encouragement and liked the feelings associated with this and this spurred them on to try and achieve more:

> ***C11**: 'I am committed to learning, because I know where I want to go, and the things I find interesting are the things I am more ready to focus on, it kind of means focusing on that particular subject instead of thinking about other things This is going to sound completely cheesy, because you don't expect a teenager to think like this but I tend to think more about my future and what it will be possible for me to do. I imagine what my house, my car and having a career will be like.'*

One mum talked proudly about how her son's determination helped him to get a job against all the odds:

> ***M4**: 'Yes he is working. He is doing good because getting a job at the moment is hard enough. You should see the boys around here in gangs they*

haven't got a job – the most they want to do is to stand on corners and cause people problems. C4 is great, he is well motivated.'

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Being a young carer – caring for parents and siblings – there were strong and conflicting feelings [from parents, children and professionals] about the role and responsibilities that children and young people undertook as young carers. The huge contribution to keeping the family together that young carers made was duly recognised by parents, children and professionals, as was the impact this had on children's lives and futures. Voluntary sector agencies tried very hard to find ways to reduce children's caring responsibilities and provide respite breaks and opportunities for children to have fun and learn new things, but still children carried out a very significant amount of care:

C4: *'Sometimes I would get up for school, this is in primary school, and my Mum would be sitting there crying or something and then she'd need something doing and I couldn't go to school because I needed to help her and my Mum is more important than school. I don't mind doing it.'*

M7*: 'C7, she just takes over she does everything and I am proud of everything she does. She irons, she basically runs the house, and she attends appointments with me. She has a diary for me because I am on so many medications so now she actually dishes the medications out because XXXX [youngest child] he's ill as well. He's got severe asthma so she's constantly looking after him with me.'*

C11*: 'My brother and sister didn't really know what was going on. I tried to keep everything going for them making sure that I kept their routine just the same.'*

Bar11: ***'****C11's caring tasks are a combination of things; it's very practical so she will get the kids [younger brother and sister] out of bed in the morning, she will give them their breakfast, she makes sure they are where they are meant to be when they are meant to be but the other thing she does, she's very supportive to her mum on an emotional level. C11 is the person who has*

the caring responsibilities really. Her younger brother and sister are impacted by the fact that mum has mental health issues but because C11 is so competent and really their alternative carer in actual fact they don't worry so much about their mum and C11 does.'

Children looking after their own health and wellbeing – children worked out what activities and situations helped them to relax and ultimately cope better with their difficulties:

***C11**: 'I love music it helps me to relax and I love singing as well. I am very involved with the school choir, I go to the Chapel to sing too.'*

Seeking out a trusted adult to talk to was one way that children used to cope with what was happening at home, another was to try and gain control by finding a way to view their experiences or manipulate their experience in ways that were easier to live with:

***C1**: 'I tidy-up my room and do it quicker so that mummy won't get angry.'*

Children sharing their knowledge and experience about what works – two children talked about how they helped professionals to gain a better understanding of their parent by giving their perspective and their ideas about what would help and what would not help their parent:

***C4:** 'They (CMHT staff) did used to talk to us outside of the house; we'd sit down and have a chat and all that. They would talk about Mum and we could help them to understand about her and what she is like.'*

Children valued peer support. Children and professionals described the important contribution that children made by listening to and offering support to others in a peer support situations. Professionals also highlighted the contribution that children made to service and professional development forums and ultimately to improving the lives of other families:

Bar5: *'I told you about her (C5) breakdown and her being emotionally drained but in other ways she can be a confident young woman and really talented musically, she writes her own music, she produces it, and she records it. She has done some jingle work for Keeping the Family in Mind and she has been able to stand in front of 200/300 people in a hall and talk about Parental Mental Health and how it affected her.'*

Different stakeholders perceptions of professionals' contributions to success				
	Parents	**Children**	**Professionals**	**Other Professionals' perspectives**
Professional knowledge and skills and experience	√		√	√
Commitment to working collaboratively	√		√	√
Being accessible, flexible and available in and out of crisis	√	√	√	√
Sticking with it – persistence, perseverance and going the extra mile	√	√	√	√
Signposting and improving access to services	√	√	√	√
Making and sustaining relationships even in difficult circumstances	√	√	√	√

Professional knowledge, skills and experience – professional activities and approaches that were particularly valued were ones that demonstrated high levels of interpersonal skills and a broad range of professional knowledge and practice experience. Professionals who thought about individuals in the context of their families whatever their specialist area of practice were praised. Whilst respondents thought that the number of professionals adopting a *think family* or *whole family* approach was increasing it was still the exception rather than the norm and this was evidenced by the way their practice was described i.e. working '*outside of their professional remit'* or '*beyond'* what is usually expected of their role.

Professionals who were: knowledgeable about what might help in different situations; about resources and how to access them; and who were willing not only to refer service users but also support service users to engage with support, were highly appreciated by all stakeholder groups. Advocating on behalf of families to negotiate the best way to deliver services was also highlighted:

***M4**: 'Bar4 arranged to come out at the time when the psychiatrist has arranged to come out from XXXX, just like for some support otherwise I wouldn't let them in on my own.'*

Personal experiences, professional training and research about 'what works' were all sources of knowledge and experience that professionals brought into play to help families. Having regular opportunities to keep up to date with policy, practice and research developments was therefore very important to professionals, as was professional supervision with a supervisor who was supportive, experienced, knowledgeable and who encouraged reflective practice and continued professional development:

***CMHT1: '**I think things have generally changed for the better in this area of practice in the last couple of years and this has affected the way I work. It's a combination of seeing the video* [training video about working with young carers and hearing what young carers have to say about their lives]*, changes in local and national policy, lessons from tragic incidents – it is the whole national picture that has changed and there is new guidance [Think child, think parent, think family,* Diggins, 2009*]. It is coming from all angles, I think this is a positive thing and I am learning from it.'*

***CMHT7: '**Bar7's experience and expertise and understanding of the psychological and other issues in the family and how they impact on and effect each other has been very important both in helping other professionals and the family.'*

***CSC3:** 'What helped me to help this family was the knowledge I have gained from my experience of working with other families. I've worked with children for 30 years now as well as adults.'*

***CMHT7:** 'I have brought my own professional and personal experience to the work. I am a mother of two young children. My husband's father had schizophrenia and I have listened to different family members talking about*

the impact this had on them including my husband's experience of growing up with a parent with a mental health problem.'

Freely sharing information (from research, professional training and practice experience) with parents and children to help them to understand what is happening to them or why a certain intervention or service is being recommended was an effective professional approach that was valued by parents, children and other professionals.

There were also a number of examples of professionals using the knowledge that they had gained about 'what works' for families to contribute to workforce development and practice change via: professional supervision, practice teaching, training and talking to other organisations about the successes in their own workplace.

Commitment to working collaboratively – professionals who were committed to working collaboratively with families and with other professionals, including getting other professionals to work in different ways for the benefit of families, were instrumental in helping families to gain access to services previously out of their reach:

Bar8: *'Challenging some of the agencies and their perceptions of what might be best for the family has been important, for example getting the school to be more aware of the family situation and to be more supportive. M8 might appear to be confident and even come across as bolshie at times, but underneath she is quite vulnerable. So just acting almost like an interpreter between the two [parent and school] so that what the family is saying is actually being heard rather than school hearing what they want to hear.'*

Being accessible, flexible and available in and out of crisis – knowing that someone is available in and out of crisis was very reassuring for both parents and children and helped to reduce anxiety in families. Being accessible, flexible and available to parents, children and other professionals were professional attributes that all

participant groups highly associated with successful professional practice and achieving positive relationships and outcomes for service users.

Sticking with it, persistence, perseverance and going the extra mile – different ways of working, different service eligibility thresholds, the stigma surrounding mental illness etc., can all act as barriers to effective working. 'Sticking with it', persistence, perseverance and going the extra mile were further attributes that parents and children repeatedly gave as being strongly associated with successful outcomes. Professionals who assertively followed up parents and young people who they thought would benefit from support were highly respected by family members that had been engaged in this way:

> ***M4****: 'When we first met Bar4 I couldn't talk to her. I would open the door and I would say – go away – and even after several months she would still keep coming, she hadn't forgotten about me she just said she would come back another day to see me. But it paid off she has been very supportive to me, she has a lot. I don't know what I would do without her now.'*

> ***Bar4:*** *'I am a quite a persistent person and I have worked in social services before in child protection and my view is the people that present themselves as not really wanting you are actually the people that need you the most. I was extremely persistent with C4. I went out even when he didn't really want me to go and I think that has impacted on C4. He comes in and sees me now, maybe just once a fortnight just for about half an hour without me asking him to come. I think I became important to him as a person that rated him at a time when his mum struggled to tell him that she was proud of him and I did that for a while. And I gave him the opportunity to do things which put him in a position where he could show what he was good at.'*

Making and sustaining relationships even in difficult circumstances – establishing a therapeutic relationship with a client was seen to be the gateway to achieving positive outcomes (see also page 207). Good relationships were not ones without challenges; in fact strong relationships were seen to be ones where concerns can be aired, difficult decisions made and relationships remain intact. The ability to

establish trust and convey respect, warmth and a genuine sense of valuing and being interested in the person you are working with, were key contributory factors to establishing a good relationship. Trust was an important factor in allowing relationships to develop to a level where families and professionals were able to retain contact and be helpful, in even the most difficult of situations:

> ***M6:*** *'Even when I have been at my lowest Bar6 has been able to make me laugh – she knows me well enough to joke with me even at the hardest times.'*

Children said they were more likely to listen to what professionals had to say and take notice of professional advice if they knew the professional well and trusted them. Children thought that professionals who took the time to really get to know them were better at organising support that worked out for them. Children found it particularly helpful if the person they spoke to also knew their parent and about their parent's difficulties.

Knowing someone is there who cares about you, that won't forget about you and who will be there in and out of crisis and overtime was very significant for parents and children helping them to acknowledge their own importance and visibility:

> ***M8****: 'I love Bar8 she has made such a difference in our lives, I am so happy that somebody has been there all the way through.'*
>
> ***C11****: 'Bar11 seems to listen to what I have to say, some people I have had to tell, they just sit there and pretend that they are listening but not actually listening. But Bar11 she will listen and ask if there's anything she can do, so it shows that she actually cares and she wants to help in some way.'*

Family contributions to success – from the perspective of parents, children and professionals			
	Parents	**Children**	**Professionals**
Whole family contributions	√	√	√
Families who are receptive to professionals support			√

Whole family contributions – close family relationships were associated with success by all respondent groups. Close families were characterised by: shared experiences that the family had lived through together; demonstrably loving and supportive relationships between parents and children; and strong sibling relationships. Older siblings, whether living at home or elsewhere, acted as confidantes and sources of reassurance for younger children and for young carers, because siblings were someone to share caring responsibilities with. Professionals believed that the likelihood of successful family outcomes increased when all family members were open and willing to engage in the support on offer.

Contributions from partners and fathers to success – from the perspective of parents, children and professionals			
	Parents	**Children**	**Professionals**
Fathers who provide parenting support in and out of crisis	√	√	√
Fathers who contribute financially		√	

Contributions from partners and fathers – fathers and partners who were willing to take on additional parenting responsibilities in times of crisis or to prevent crises and who understood the fluctuating nature of and vulnerability associated with mental illness were seen to be particularly supportive (although examples were rare). Children were very aware of the support that their father or mum's partner provided to their mum and themselves:

> ***C1:*** *He [mum's partner] buys me things that I need and he helps Mummy with the bills and money for the shopping. Mummy doesn't have to worry about the bills then.'*

> ***CSC3:*** *'The boys spend a fair amount of time with their Dad at weekends and during the holidays and M3 if she feels the boys are getting a bit too much she will phone dad and he will come down. Dad would be the one to take them out and do things with them more than mum. I think the outcome for the boys would be a lot different if dad wasn't around and being supportive.'*

Contributions from grandparents to success - from the perspective of parents, children and professionals			
	Parents	Children	Professionals
Grandparents acting as primary carers	√		√
Paternal grandparents providing practical and emotional support to mothers	√		√
Providing practical and emotional support to grandchildren	√	√	√

Contributions from grandparents – maternal and paternal grandparents featured strongly in a small number of the families. In *Case Family 2,* for example, the maternal grandparents had been primary carers for their daughter throughout her adult life and provided consistent practical and emotional support to their daughter and their two grandchildren. Continuing as the primary carers for their daughter has enabled their grandsons to avoid becoming young carers. Other grandparents had provided parenting support by providing a listening ear to parents and helping to take care of grandchildren. A close and loving relationship with a grandparent was very important to children.

> ***M2**: 'I tried to make sure that all the things I did with them when I was Mum, my Mum [maternal grandmother], sister and brothers picked up on the same things when I was not there [in hospital] or not able [too unwell] to do it. Where we come from we have standards....I cooked a lot and through all the madness I still never went and bought them TV dinners or anything. You don't want to leave your child damaged.....for example....when it comes to school work, it comes first. I think education is important.'*

Contributions from extended family members, friends and the church			
	Parents	Children	Professionals
Extended family	√	√	√
Friends	√	√	
Church Community	√	√	√

Contributions from extended family members, friends and the church – extended family members who were aware of the family's difficulties were important sources of contact for families, particularly those who were otherwise isolated (see also – *Final outcomes as success – safety as success,* page 120):

***C10a**: 'My aunty and uncle are really helpful because they understand and I go around to their house. My Dad's wife understands as well.'*

Parents and children talked about the important role friends played in their lives, particularly friends who they had known for some time, who knew about their difficulties and were prepared to stay friends when times were tough.

Two families were closely involved with and received support from the church community. The benefit for the first family was about pursuing their religious beliefs and feeling part of the church community; for the second it was also the long-term emotional, practical and financial support that members of the church have provided.

Summary

The quality and sustainability of individual and collective contributions to success clearly influenced the likelihood of whether parents, children and families would be able to access and benefit from interventions. The determination of parents to keep their families together, and children's loyalty and love for their parents, were powerful characteristics and contributory elements of success visible in all of the families. Parents and children also invested a lot of effort and emotional capital into the successful relationships with professionals that they described. Similarly, professionals demonstrated high levels of interpersonal skills and drew on different aspects of their professional and personal knowledge and experience to achieve relationships that worked. When relationships worked well between service users and professionals, and inter-professionally, the pathway to success was less encumbered.

Parents used the knowledge and new insights they had gained from working closely with professionals and in peer support situations to make significant changes to their relationships, particularly the way they communicated with each other. When their efforts were successful this increased their confidence which provided the impetus to do more. Children demonstrated a complex array of coping strategies to help them manage their situation, including their caring responsibilities. Young carers were highly regarded for their contribution to keeping the family together, but these comments were overshadowed by the impact that caring was having on these

children. Having a positive outlook and striving to do well and having goals for the future provided an important focus for children.

Positive and supportive contributions from other family members, extended family members, friends and the church were crucial to the survival of some families. Support from these sources included: reassurance; shared parenting; help with childcare; financial support; help in a crisis; friendship and love and reassurance. Children in particular valued the contact and comfort they drew from relationships with family members who lived close by. Few families though benefitted from this kind of support.

Professional activities and approaches that were particularly valued were ones that demonstrated high levels of interpersonal skills and a broad range of professional knowledge and practice experience. Being knowledgeable about what might help in different situations and how to negotiate resources on behalf of families was highly valued. A commitment to working collaboratively with other professionals and the family, being accessible, flexible and available in and out of crisis and being prepared to stick with families and go the extra mile if necessary were all characteristics associated with successful practitioner support. Perhaps most importantly to families was feeling safe in the belief that there is someone there who cares about you and what happens to you, that won't forget about you.

BARRIERS TO SUCCESS (4)

The final aspect of success concerns different stakeholder views about the major obstacles that stand in the way of success or have to be negotiated to achieve success. There are three sub themes in this data category, which are: barriers between families and service providers; isolation and exclusion; and the nature of families' difficulties.

Barriers between families and service providers	Number of respondents
Total number of research respondents who talked about this theme	33 (68%)
Parents who talked about this theme	10 (84%)
Children who talked about this theme	7 (60%)
Professionals who talked about this theme	16 (64%)

All of the case study families had experienced conditions such as poverty/low income, chronic unemployment, social isolation, illness/disability, violence and discrimination, and for whom basic survival is a difficult task. Parents and children spoke about the hopelessness they felt about their situation and how their hopes had been repeatedly quashed by a series of unsuccessful attempts to achieve a better life for themselves. Parents blamed themselves and felt responsible for their situation. As a consequence they had been reluctant to seek help from statutory services, in part because they felt their request for help would be met with criticism and not asking for help was a way of avoiding this.

When they did try to get help the complex array of services and different professional roles and responsibilities were not always explained very well leading to confusion about who does what and why and who they needed to go to for information or when there was a problem:

> ***M9:*** *'CMHT9, she was the mental health social worker but I didn't realise the difference, it was confusing because we had a child social worker. Some of it has not been explained that well.'*

Parents wanted more time with professionals to reflect on their difficulties (CMHT, CSC and CAMHS staff in particular) and felt professionals were too busy to provide this. Parents and children believed that if professionals spent more time getting to know them as people, as well as well as finding out about their difficulties, there was more chance that the support they offered would be effective. All of the parents and children had experienced interruptions in support or very limited support when they

were waiting for their case to be allocated or when a worker left or was off sick for a long period of time:

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> ***M1: 'I see a woman called XXXX she's new. She comes but when she comes she seems like she's waiting to go.'***
>
> ***M10:** 'Well the psychiatrist doesn't know me, no...It might as well have been the milk man because every time I have gone to see her I have seen someone new so there has been no continuity.'*
>
> ***M7:** 'I have seen a psychiatrist but they always change, always seem to change somehow, and it took 12 months before they allocated me my first CPN and then she left.'*
>
> ***M9:** 'Well I am supposed to still have the social worker but she's on long-term sick leave at the moment and there is nobody to take her place.'*

Children were also concerned about the barriers that get in the way of establishing and maintaining an essential trusting relationship with a professional, and the loss they feel when those relationships end:

> ***C12:** 'When I went to year six there was a school mentor change, because one of them got ill and then the other one moved. I missed them when they went as I saw them quite often.'*
>
> ***C9a:** 'Social workers they always move on from places just when you are getting somewhere with it as it is hard to build that trust. Then you have to start all over again to get that relationship where you can talk about stuff. I find it really hard to talk to Bar9 about stuff.'.*

The short-term nature of some interventions, and the inconsistency that arises from frequent changes of professional, resulted in feelings of loss and abandonment for some parents and children, and difficulties when they had to start all over again with someone new.

Most parents did not want to talk in detail about their mental health problems with other family members, including their own parents and their children's fathers. For all but two families this meant that there was no other adult in contact with the family who was aware of what happens for children on a day-to-day basis at home. Professionals in adult services did not routinely engage with children in the family to find out what had been happening with their parent or whether they had difficulties of their own. Childcare professionals also shied away from speaking to children, parents and other family members about the impacts of parental mental health on parenting and the child. Instead, professionals relied heavily on what mothers had to say about how their child was coping. Professionals tended only to involve extended family members, including those who were consistently providing support, when there was a crisis:

> ***M3:*** *'I talk to the children's dad and they [ex-partner and his parents/paternal grandparents] know that I am involved with the XXXX [CMHT] and they have got the XXXX [CMHT's] telephone numbers if I do become ill.'*

There was only one family where older children/young carers in the family were routinely involved in their parent's formal assessment and care planning processes (CPA). Children were generally aware of different professionals visiting the home to see their parent or their parent going out to appointments, but could not say who their parents were seeing or for what was happening:

> ***Bar5:*** *'When the CPN used to come to see her mum, they used to send her [child] out of the room and say "can you go away while I talk to your Mum", which I found bizarre. Then they would ask mum how she was and she would say, "I am ok, thanks", when, actually last night she was in her pyjamas going down to the docks – if they had spoken with C5 she could have told them that. This young woman is with her Mum 24/7 and knows the ins and outs of her mental health. And I know there are issues about "confidentiality" but to never really speak to her and never ask her the question, "how are you?", and "how is your Mum?" - it is bizarre.'*

Professionals admitted getting permission from parents to talk to their children could be uncomfortable and problematic and some parents refused. They also conceded that not doing so, or not being granted permission, resulted in only a partial picture of what was going on in the family:

> ***CMHTMan3:*** *'....it's about whether or not the parent will want the child to talk to you. There are a whole lot of issues. If the child is older they might be able to benefit from talking to a professional about what their parent's mental health issues are but some parents think they are exposing their children to too much and some parents don't actually want to accept that their children are actually caring for them. I do think it is very hard for parents to acknowledge that they are relying on their children.'*

Difficulty accessing services

Parents, children and professionals highlighted a number of issues about the accessibility, timeliness and continuity of support. Professionals, particularly in the voluntary sector, believed that without an advocate, service users who found it hard to access help in traditional ways (e.g. go to the office for appointments) would not have been able to benefit from services that could help.

Year on year, financial cuts, coinciding with increased demand for services, led to a reduction in resources in the two research sites and service eligibility criteria rose. As a consequence, some families did not get the resources that were identified and recommended for them in Child Protection Plans and parents' and children's needs and wishes did not always 'fit' with the resources that were available. There was a strong theme coming from the voluntary sector and CMHT staff that CSC services needed to be more involved with families and for longer. There were several examples of referrals to CSC that were rejected because the eligibility for assessment and services in CSC was too high. High service eligibility thresholds in CSC meant that, for some families, CSC were only involved on an intermittent basis, largely in response to crises, and examples were given about how this resulted in unsatisfactory experiences for a number of families:

CMHTMAN3: ***'****Well I would say that the issue for myself and perhaps for a lot of people here in the CMHT is that when we feel there needs to be intervention from the children's services and we complete a CAF referral form that they invariably don't offer any resource because they seem to be so under-resourced. This is for when we think they need to intervene, either to offer direct support for the child or to monitor the impact of the parents mental health on the child. I think in this day and age you know in most social services in London that this is very difficult.'*

Bar10: ***'****The local authority children's services have been involved periodically and haphazardly and that experience of involvement has been difficult for the whole family. The family felt they were promised something that didn't actually happen and the case [and Child Protection Plan] was closed without any negotiation, without the resources that were promised materialising and it was quite a difficult time for the family.'*

There were also examples of '*one size fits all'* provision or gaps in transitional eligibility criteria between children's and adult services that resulted in individuals falling through the '*service net'*. For example a number of children had not attended school for long periods of time (up to three years) and the professionals supporting them found it extremely difficult to find suitable alternative education. These children were missing out on their education and spending long periods at home further exposed to their parents' difficulties and becoming more and more isolated. Secondly parents with younger children not attending school missed appointments for themselves because they could not leave their children at home alone and could not take them with them to appointments about their mental health. A third example was young carers who were 'too old' to receive young carers support, but not 'old enough' to be eligible for adult carers support.

Bar 9: *'C9's older twin sisters are now in the 20s and living away from home. They're still in that caring role and relate very much to the project and I guess that's because there's a gap in services out there but also because there's something about the relationship that the family develop with us.'*

Barriers to inter-agency working together

Professionals were not always aware of, or took active steps to, find out who else was working with the family. Professionals gave a number of reasons for this. Some parents were described as 'manipulative' and deliberately 'hiding information' from professionals, possibly because of the stigma associated with involvement with statutory services. Professionals said some parents '*played one service off against another*' because they had '*difficulties relating to authority figures*'. However, an alternative explanation offered in the data is that professionals in all agencies did not routinely and proactively take steps to identify and communicate with other professionals supporting the family, at the time of taking on a case or afterwards. There were few examples of staff successfully challenging parents when they thought they were withholding important information, or challenging other professionals when they were not routinely invited to important meetings; for example, case reviews or safeguarding meetings. There was a certain acceptance that '*this is the way it is'* and nothing can be done, because it is part and parcel of '*professional cultures'* that are too hard to shift, and as any improvement was someone else's responsibility to address:

> ***Bar7:*** *'What happened was, CAMHS did the initial work of getting everyone together. That was how I became aware that there was not just me involved and there were in fact a number of professionals involved with the family that had not contacted me, e.g. there was a post natal depression person involved, there was a play worker, there was the learning mentor at school, social services, CAMHS Working Together Team including an adult psychologist. There was a raft of people and I hadn't had a conversation with any of them.'*

> ***BBPrac1:*** *'I am not invited to CPA review meetings. It's really difficult to get invited, but that could be something to do with M1 as she likes to keep agencies separate, which is something we need to work on really. She has had the children and family intervention team involved too and we were not aware of that and M1 actually kept that quiet for quite a bit.'*

Some professionals complained about the length of time that service users waited to be seen by services that they had been referred to. Waiting resulted in a further deterioration in some parent's mental health, which in turn reduced their motivation to take up services. When referrals formed part of an integrated care package, difficulties arose when some parts of the care package started and others were seriously delayed. The following two examples took more than six months before the referral was even considered by the referred to agency:

> ***CSC3:*** *'The original referral came in (from the CMHT) in February, we then started looking at it and it wasn't until about August actually that things started to happen. We had tried to contact CMHT3/referrer but she was off sick, so it was August time before we got the health visitor involved then she took on the role of referrer and the process carried on....'*

> ***Bar6:*** *'The request for an individual budget took six months just to get to the panel for a decision* [for a Direct Payment to pay for a personal assistant for mum M6] – *during this time C6 was carrying on giving the same high level of care to her Mum.'*

<u>Isolation and exclusion</u>

Parental concerns about their children were repeatedly not responded to or taken seriously particularly by education professionals. Several parents who were interviewed (and parents in the focus groups) described very emotionally the difficulties that they had had getting teachers and special educational needs advisors to take their concerns about their children seriously. As a consequence, these children were not offered appropriate screening, assessment or early intervention. At least half of these children waited for at least a year - or in two cases two and three years – before they were properly assessed. Those that were assessed were ultimately diagnosed with a range of difficulties including: moderate and severe speech and language difficulties; dyslexia; ADHD; learning difficulties; depression; anxiety; serious academic delay; and physical health problems, including borderline diabetes for one child. No apologies were given to families when assessments finally validated what parents had been saying, or for the delay caused by professionals who had not listened or responded appropriately to parental concerns:

M8: *'He used to cry about going to school because he wasn't really getting help and they looked at him and said 'he's alright' but I knew in my heart and soul, that he was not right, he was not grasping stuff, I had XX [older brother] to compare him with so I knew something was very wrong as XX [brother] has dyslexia as well but C8 had more difficulties. He was behind and stuff although he was in small groups. It took such a long time and he got more and more withdrawn. It used to break my heart and they never signposted us to anybody that could help.'*

A number of obstacles were identified that get in the way of children enjoying their school experience, achieving their potential and reaching academic milestones. Some children had chronic problems with punctuality linked to their parent's difficulties, for example, parents kept children at home because they were frightened of being alone; or they were not able to take children to school or collect them because they stayed awake all night and slept during the day. Other children were bullied at school. Once children had stopped going to school, supporting them back into mainstream or specialist education was extremely difficult, with some missing several years or not returning at all. Professionals explained that the range of support and alternative to mainstream provision on offer was very often set up for, or populated by, children with significant behavioural issues, and the children they wanted to refer did not 'fit in' with this group. Long periods out of school significantly affected the health and wellbeing of a number of young people:

C5: *'No I am not in school and I don't really do anything. I've got quite isolated. I'm used to being indoors a lot so it's a big effort even going down the shop or something like that. But I would like to go to college I want to be a make-up artist.'*

Bar5: ***'****We tried three alternative education placements which unfortunately have mostly young people who have either been excluded from school or referred from custody and they have significant behavioural issues and C5 just doesn't fit into those groups and there's nothing in between, there's nothing for young people like her.'*

Isolation and loss was a central theme in discussions about obstacles to success. Families and professionals saw isolation and social exclusion as a key factor impacting on all of the families. Families lost touch with partners/fathers and extended family members, often because of parental mental health and the stigma associated with it. The majority of the families had few social contacts, friends or positive experiences with neighbours. Symptoms of mental illness made it difficult for some parents to leave their home and two parents with agoraphobia had not left their home alone for over five years. Having very small family and social networks meant that any loss was catastrophic, leaving some parents with no one that they could confide in, enjoy a relationship with, or be supported by.

When parents become estranged from other family members, children become isolated too, and this was something that young people found extremely difficult. Making and maintaining friendships with other children was also difficult for a number of reasons, including: children having to stay home to look after their parent; not being able to bring friends home; and not knowing who to talk to because they were embarrassed about their situation or because they were preoccupied with what is happening at home.

> ***C10a:*** *'When I was a little girl in primary school, when your Mum has mental health problems you tend to think it's normal and it took me a few years actually to realise that my Mum was sick and wasn't like the other mums. Probably like year 3 or year 4 when I realised my Mum is, not as I thought.'*

> ***C10a:*** *'I didn't actually make friends in my secondary school and I didn't really have any at primary school.'*

Despite the important role that close and extended family members can make, they were not routinely contacted, supported or involved in assessment and care planning processes by any of the agencies involved in the study. Neither did contacting, helping to develop and supporting relationships within the wider family appear as a safeguarding or mental health and wellbeing goal.

Socio-economic circumstances

Parents who had worked previously said that their career and employment was interrupted and not returned to once they became parents. Trying to bring up a family with little or no support and trying to hold down a job was '*too much'* for parents and they were unable to continue to do both (as sufficient support was not available) without becoming repeatedly unwell:

> ***Bar8:*** *'She is an intelligent woman and initially when I met her she was doing a teaching course but she didn't have any help and she just couldn't go on with it really which was a shame.'*

Parents who had made significant strides in their mental health recovery felt under pressure, mostly from themselves, that the right thing to do now was to get a job, but they were fearful of the consequences of doing so. Some recognised that whilst they did not feel able to hold down a job, they did need to be occupied, get out of the house and spend time with other people on a regular basis. Professionals encouraged parents to take up training and other opportunities, however, many of the courses on offer were at a very basic skill level and did not take account of service users' existing knowledge and skills, and there was little opportunity to progress to more advanced courses. Parents perceived advisors on the one hand to be encouraging them to get back to work, but on the other hand to be demonstrating low expectations of what service users could achieve:

> ***M2:*** *'I have to keep occupied, I don't sit here idly. I have always got some sort of project. But I don't know if it is feasible for me to go out there and be a retail manager again. Things have changed.'*

Living in poor housing or troublesome neighbourhoods were primary examples of obstacles to success for affected families. Children were acutely aware of the impact that living in poor conditions for long periods of time had on their parent's mental health, and how this was exacerbated by the battle that parents had with housing providers. A major stressor for parents was getting their housing providers to take their concerns seriously, piling on further stress and frustration.

All of the families interviewed received some form of welfare benefits and continually struggled to make ends meet. Parents and children talked about how never having enough money meant that they did not get to experience things that other families took for granted, unless they received financial support from the organisations that supported them. Children were very aware that if their parent was worrying about money or bills then this could lead to them becoming unwell:

> ***C8:*** *'I worry about it [deterioration in mother's mental health] like because if she gets bills or something then she gets stressed and can't get it out of her mind and it's been like this for a long time.'*

Problems with identifying child mental health problems

Some professionals did not recognise when children's emotional and behavioural difficulties had reached a level that required intervention.

Problems with identifying child mental health problems	Number of respondents
Total number of research respondents who talked about this theme	28 (56%)
Parents who talked about this theme	8 (67%)
Children who talked about this theme	7 (59%)
Professionals who talked about this theme	13 (52%)

Some children had significant emotional, behavioural and mental health problems; including depression, anorexia, self harm and attempted suicide. Despite children being known to services, the majority did not receive specialist intervention for mental health problems until they had reached crisis. Most children were never really free from worrying about their parent, including the fear that their parent would die, harm themselves or commit suicide. As a consequence, children went to great lengths to protect their parent; including not going to school and staying at home to be with them. It was difficult for children to know who to share their worries with and how (or whether, if they were frightened about the response) to convince them just how difficult things were at home:

M5: *'I thought she (C5) was depressed. She was sleeping all the time and she wasn't eating and all that and she just constantly worried about me. She was depressed. We (M5 and Bar5) took her to Alder Hey Hospital and they said that she was unhappy. They had to keep her in because the psychiatrist said she was really depressed and he had a talk with C5 and she mentioned that she felt like killing herself. I could see her going down, downhill.'*

C5: *'I was really worried about my Mum, it lasted for a few weeks. I put up with it and then I told my sister but my sister didn't really think anything of it because she wasn't seeing it every day. Then one day she (M5) flipped quite a lot and then I just ran out of the house and went to my sister and just left her in the house. Then my Mum got took to hospital and I got referred here [Barnardos Action with Young Carers].'*

Not all professionals involved with families were aware of, spent enough time on, or were confident in assessing, whether children in the family had difficulties of their own. This was made more difficult when children found it difficult or embarrassing to talk about what is happening at home. Some children felt that their needs got lost because all of the attention was on their parent and some professionals worried that whilst the child's needs might not be obvious then, they could be storing up problems for the future:

CMHT11: *'She's been a young carer for quite a few years by the sound of it without anybody really picking up on that.'*

<u>Carers and caring</u>

Carers and caring	Number of respondents
Total number of research respondents who talked about this theme	15 (31%)
Parents who talked about this theme	3 (25%)
Children who talked about this theme	2 (17%)
Professionals who talked about this theme	10 (40%)

Young carers carried out a diverse range of caring responsibilities, some of which impacted their own health and wellbeing; including their mental health, education, friendships and their relationships with family members. Their own parenting needs, in contrast, were at times significantly unmet. Professionals said that children struggled to juggle their responsibilities at home with school, resulting in unacceptable levels of stress and unhappiness. Parents and professionals also identified the strong reactions that occur when parents feel better and want to reclaim their parenting role:

> ***Bar8:*** *'C8 came to us [to Barnardos] when he was nine or 10 years old because it became evident that C8 was helping his brother with his Mum's physical care like washing his Mum's hair and it wasn't appropriate. She was very low and the older brother was trying to get her to wash herself and change her clothes but it was difficult and she is a quite a big woman so physically it was difficult for the boys too.'*

> ***M9:*** *'.....and she (C9b) admits it herself anyway, she molly coddles them boys [younger siblings] and that was great when I wasn't well but when I was well again I would be like 'I can do my duties now so back off a bit' but she couldn't you see. No, she'd found herself a little place and she wanted to keep it, so we were at loggerheads about that.'*

Parents and professionals consistently praised young carers for their contribution but were also very worried about the excessive amount of caring they undertook. Despite this concern, it was also difficult for parents and professionals to see how families would survive without this input:

> ***Bar11:*** *'There's definitely an impact on C11 in terms of the way that she spends her time. C11 splits her time almost equally between household stuff and school. She's extremely diligent and very, very interested in doing well in school. She wants to become a lawyer, that's definitely her plan. C11 presents as being so competent and so OK but sometimes I would see her when she's been so stressed trying to get things done for school but trying to balance it with the stuff she's doing at home.'*

C6: *'Yes, I look after myself quite a bit and I have to look after the dogs, I've had one dog since I was seven, so I look after them and clean up after them. I look after my Mum [she has mental health and physical health problems] like when she wees in bed I clean the bed for her and help her in the shower. Our XXXX [brother] cooks for her when he gets in from work; I just make the other meals and things. But I worry about my Mum.'*

Adult mental health and parenting

Adult mental health and parenting	Number of respondents
Total number of research respondents who talked about this theme	26 (54%)
Parents who talked about this theme	10 (84%)
Children who talked about this theme	3 (25%)
Professionals who talked about this theme	13 (52%)

Parents talked about the different ways that mental illness gets in way of all family members living their lives in the ways that they want to. The stigma surrounding mental illness impacted on parents and children to the extent that some children had been bullied and family members had become estranged. Fluctuating and dramatic changes in symptoms and behaviour can be distressing for children to witness. And parents described having to 'summon up the strength to keep going for the sake of their children'. Some parents who thought they had been coping whilst they were unwell were surprised, in retrospect, to find that they had not been coping at all. Professionals also described a range and intensity of different symptoms that overwhelmed parents at times, affecting their ability to carry out daily tasks and maintain their relationship with their children:

M9: *'When I am depressed I think I tend to overdose then but when I am going high and I can't cope, it seems more erratic stuff I do like use a knife or the scissors to cut all my hair off.'*

M3: ***'****I wasn't managing the boys too well****,*** *I thought I was but I wasn't, they would run off down the road and I wasn't able to manage them and inside of*

the house as well. I think it was all a bit too much, I didn't know how to set boundaries and they didn't have any. I wasn't going out with the children either, I was just staying inside my four walls. They used to go to school but I left them there, because of my feelings I had to ring for a taxi to go and get them and bring them home.'

There was a strong association between mental and physical health problems for a number of parents who had life-threatening or chronic illnesses. Physical health problems exacerbated mental illness and mental illness contributed to deteriorations in physical health. There was a further relationship established between drug and alcohol misuse as a contributor to, or something that exacerbated, poor parental mental health. On the whole, parents showed little insight, or were unwilling to acknowledge, that their use of cannabis or other drugs or alcohol (as a way of 'self medicating') decreased the effectiveness of their treatment, and increased their vulnerability to relapse.

Psychiatric medication, like other medication, can have adverse effects and this was given as a primary reason for non-compliance. Even when it was experienced as beneficial, medication still left all of the parents interviewed feeling disappointed that it could not give them complete or more respite from their difficult feelings (see page 154 for more findings about taking psychiatric medication). Some parents were fearful about the long-term impacts of medication:

M2: *'I have lost a number of people I got to know in the services [mentions three names] and I know at least 10 people who have died and it's got to be to do with the medication and everything else and these were young lives.'*

The majority of parents felt that they had failed as parents or were bad parents and that feeling like this only made their mental health problems worse. Some of the illnesses experienced by parents can engender feelings of guilt, complicating the matter further. Children were reluctant to talk to their parents about their own problems because they didn't want to make their parents feel worse. Trying not to increase parent's guilt was a priority for some professionals too. There was incongruence between parents' descriptions of the strong and overwhelming feelings

of worry and guilt they felt about their children and their parenting and the extent to which they thought their children had been negatively affected. The impacts they described were far less intense or extensive than those described by their children and some professionals:

> ***M7:*** *'I feel a failure, if you've got depression and you're nervous you are not a very good mum. Your mind is somewhere else when it should be on the kids really, shouldn't it and I feel guilty and I hate feeling that way. I think the children have been affected emotionally because of this.'*

> ***Bar7:*** *'I meet mostly with M7 and I made a decision fairly early on, not to meet very often with C7 and the reason for that is that the nature of M7's illness is such that she sees any attention to her children as something to do with her mental health, 'So I am so horrible and so mad that somebody else has to do work with my children'. That's how she views it.'*

Summary

The interconnected nature of different *elements of success* was most apparent in the data about *barriers to success*. Unsurprisingly, many examples in the findings about final and intermediary outcomes of success were about overcoming the obstacles that are set out in the findings about *barriers to success.* Parents, children and professionals were very keen to tell their stories about the barriers that had previously got in the way of achieving improvements, or in some situations continued to make things worse. Accounts of the barriers that got in the way previously – for example, the stigma service users experienced trying to access services – served to put up more barriers, deterring families from seeking help in the future. This made descriptions of overcoming these barriers even more significant. By understanding the barriers to success the contributions to success highlighted in the previous chapter and the first part of this chapter become even more apparent.

Parents and children wanted professionals to spend more time getting to know them to get a clearer idea about the origins of their difficulties and to listen and act more on their ideas about what would help. Families believed that more attention and resources to help with the underlying causes of their problems would result in more

sustainable and beneficial outcomes (poverty, poor housing conditions, unemployment, discrimination, racism). Cuts to services due to financial constraints; high service eligibility criteria that does not take into account the combined needs of different family members; and the stigma associated with mental illness and seeking help from statutory services, combine to make access to support very difficult. Problems with the timing and timeliness of interventions prevented individuals and families getting help when it can be most effective. Long waiting periods whilst a referral is being processed resulted in a decrease in service users' motivation to take part and delay in identifying the emotional and mental health needs of children meant some children were left alone to cope with their distress for long periods without any help.

CASE FILE REVIEWS

The file reviews supported the findings from the individual interviews with parents, children and families. The files were also helpful in providing some of the background information about families and their circumstances. However, it was clear that some (but not all) parents had minimised the issues that gave concern to CSC and other agencies over time, for example: concerns about neglect; emotional abuse; and parental substance misuse. All files had gaps in information about the assessments and activities of other agencies and little recorded evidence of inter-agency planning, with the exception of two cases in Barnardos Action with Young Carers Project. There were a number of sources of information that I fully expected to find in the files that were not there. Perhaps the most stark omission was that the child's voice appeared to be missing from the statutory service files. There was extremely scarce record of conversations with children about their situation, their experiences and their wishes. The majority of recordings about children were in regard to what the parent (the parent with mental health problem) had to say about how their child was feeling and managing. In CSC, CMHT and Barnardos Action with Young Carers files (Lewisham Building Bridges files were not available for review) it was evident the efforts to involve other family members, including the children's fathers, were few. Whether families were estranged or indeed providing significant support, efforts to engage other family members were minimal outside of crises. There were no chronologies on files that would have helped to view service

involvement and significant incidents over time, despite some families being known for many years to services and having experienced multiple difficulties and events.

FOCUS GROUP FINDINGS

Findings from the three focus groups corroborated many of the findings established in the individual interviews (to avoid repetition these themes are not set out again here). New themes or issues that were given more clarity through the interactive discussion are as follows.

Parents

Parents in the focus shared concerns about getting professionals in housing and CSC to understand their difficulties and the concerns they had about their children. Problems with getting school staff to understand and respond to concerns about their children's problems in school were very high on parents' agendas and supported the findings from individual interviews. Children with special educational needs did not get identified and supported until sometimes years after parents voiced their initial concerns.

> ***Parent:*** *Schools just don't understand. They (children) can't just disconnect. A child cannot switch off from what is going on outside and the school doesn't ask them what's wrong – they just see the child 'going off on one' in school, just what is happing in front of them not the reasons why and they (children) just get labelled disruptive.*

> ***Parent:*** *I think education has a lot to answer for. If they aren't doing their job it is impossible to get things sorted out if you haven't got a social worker it is impossible to sort things out yourself and that just adds to the way you feel. It has a knock on effect. And now that Barnardos (see explanation below) is withdrawing it will be impossible to sort things out.*

Some parents were frustrated that the focus of professional concern centred on themselves and this made it difficult to because of this it was difficult to get anyone to listen and act on their concerns about their children and high service eligibility criteria made this even more difficult:

Parent: *Sometimes the mental health workers can't work around the child. From my point of view it is limited. They don't talk to us about our children. Any conversation I have had with my (CMHT) social worker about the children he has not known where to refer them to. It is unfortunate that you can't have a social worker that is trained to work with all the family like it used to be.*

Parent: *One of my sons has problems but he's never been connected to anything that can help. It seems to be all about settling my issues and I think that has been the biggest gap. Years ago I was able to count on my social worker when they took a broad family approach. But those things have all changed now, everything is separate. I have cried out to CSC but they have said "oh he is not extreme enough, so we can't help".*

Parents (who all came from Liverpool) were aware of and extremely complimentary about Barnardos Action with Young Carers and the work that a number of organisations were doing together in Liverpool to improve outcomes for families – some parents had been involved in these service improvements. Parents particularly liked the way that the whole family could engage with the Barnardos Project and that support was available for longer periods. The relationships they had built with the project helped them to feel cared for and safer than they had before and they trusted that the staff had their children's best interests at heart even when project workers had to address concerns about their children or problems with their parenting. There was concern however that as a consequence of cuts in funding the staff team at Barnardos Action with Young Carers had been reduced and one consequence of this was some families were being offering a reduced service.

Long term support and attention to the fluctuating needs of families was also raised especially the reassurance gained from knowing that someone else was there to think about children when the parents could not:

Parent: *If in your state of mind (unwell) you are trying to cope but you can't see further than that to see whether the kids are OK and things might be harming them and it might be too late then and the damage is done. But*

there is no one there to check if everything is OK and whether the children are OK. Workers might think everything is OK but they need to check with the children.

Children

The emotional intelligence that children displayed during the focus group was, for me, overwhelming. The children were by far the 'best' at '*telling the situation as it really is'* in regard to what happens in their family. This was also saddening as due to their protectiveness towards their parent, many were left alone for long periods with their worries and fears. With the exception of two young people (who were angry about some services), children resigned themselves to the difficulties that professionals had in understanding their parents. They talked about how professionals accepted what parents told them, when in reality the situation was different – for example, parents reported that they were feeling okay, when in fact their mental health was deteriorating. Children with one exception were "*okay*" with their role as a young carer and the majority were proud of how they helped their parents and siblings, but did not always want their friends and other people to know about this. They were extremely thankful for the support that Barnardos Action with Young Carers Project gave and they liked that staff knew both their parents and themselves, as this made it easier to talk about things at home. They 'loved' spending time with other children and having fun and were happy about some of the opportunities they had been given to pursue particular interests or things they were good at. Having a break from home was very important to these young people. Some teachers and school learning mentors had made it possible for children to enjoy their school lives by closely supporting them at school and making the connection between school and home.

Professionals

The multi-professional focus group discussion highlighted the frustration that different professionals feel about not being able to do more for families more easily. Voluntary sector professionals were more satisfied with their role and had many positive examples to share about family successes. The primary barrier for voluntary sector professionals was the uncertainty and insecurity of short-term funding, which made it difficult to build on successes as they would like to and having to cut or dilute

services that were '*successful'* because of cuts to funding and changing bureaucratic priorities. Statutory sector agency workers were strong in the belief (and their voluntary sector colleagues concurred) that thinking about whole families was much easier to do that it had been previously, but that the balance between prevention and acute services had not so far been achieved. Many of the participants in this group were managers and they were concerned that new professionals had not necessarily had sufficient training or practice experience to help them to deal with the complex problems that some families had. They were also concerned that given high turnover of staff in CSC and reduced numbers of staff it was more and more difficult to support new staff to acquire the right experience and skills. One senior CMHT practitioner in the group, with many years of social work experience, openly (and bravely) explained that due to her fear of getting something wrong, and because there was just too much work anyway, she avoided contact with her clients' children, and she felt this was the same for other professionals that she worked with.

> ***Professional:*** *Adult mental health workers often work with adults (parents) longer than other agencies do and we get to know them well and their histories. But I have been working in mental health for a long time but I am still reluctant to get involved with children in the family and I think it is the same for a lot of my colleagues. It is a case of not seeing the children means you don't have to ask questions that you might not want to know the answers too. It avoids getting it wrong and making it worse.*

Summary

In the next chapter the findings about success (from chapters 7 and 8) and the themes and the relationship between them will be discussed, in the context of the evidence set out in previous chapters in this thesis and the existing literature. The different elements of success illustrated in Diagram 3 will be used to structure the discussion.

CHAPTER 9 – DISCUSSION

INTRODUCTION

This chapter sets out the extent to which the research findings answer the primary research questions; by discussing the relationship between the research themes in the context of the existing literature and the context in which the research took place. The chapter begins with a summary about what parents, children and professionals had to say about *success*. Key aspects from the six overarching themes about success are then discussed. The final section of the chapter reflects on what focusing on success has contributed to our understanding and evaluation of parental mental health and child welfare work. Reference will be made to the differences and similarities between different participant views.

The starting point for this study was *success*. All of the case study families taking part had experienced '*success*' in one form or another in the 18–24 month period prior to the start of the research. There was a great deal of consensus amongst different stakeholders (parents, children and professionals) about '*what works*' in parental mental health and child welfare work and what needs to be in place for successful outcomes to be achieved. There were also some important differences.

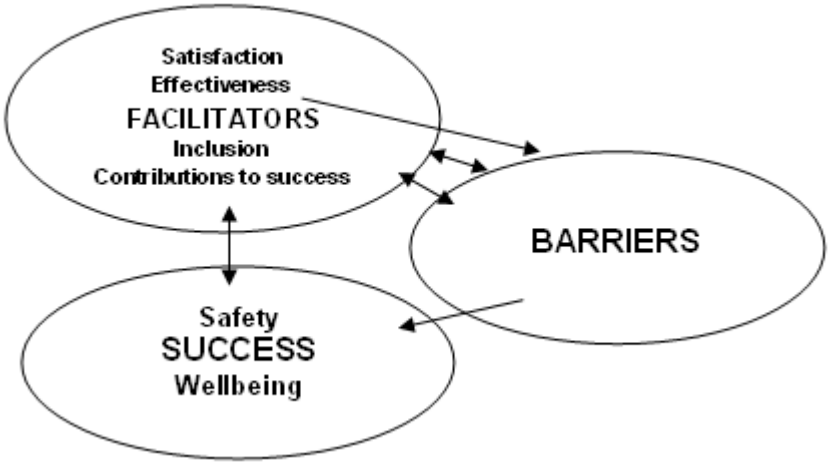
WHAT PARENTS, CHILDREN AND PROFESSIONALS HAD TO SAY ABOUT SUCCESS

Participants liked talking about success but rarely had the opportunity to do so. It was difficult for all participants to talk about what had worked out well without talking about the difficulties and barriers they experienced too.

Success is dynamic, not static. For example, an improvement in the relationship between a parent and child (success) may be the result of improved parental mental health facilitated by effective treatments, and this might have been further facilitated by the commitment a parent and professional had made to their client-professional relationship. The same outcome for another family might have involved the need to overcome some barriers along the way. An example here could be overcoming a parent's suspicion and fear about taking medication or having difficulty trusting a professional's recommendation, based on previous negative experiences (barriers).

In this case, further facilitation may be needed to overcome or negotiate these barriers before a final outcome is reached. A significant number of *intermediary* examples of success were about negotiating and overcoming barriers to success that had previously been too difficult to surmount (see Diagram 4). These examples were particularly important to parents, and, in many cases, as important as *final* outcomes of success.

DIAGRAM 4 Pathway to success



SAFETY AS SUCCESS

The themes that will be discussed here are:

- Minimising risk and risk avoidance
- Interventions targeted at reducing stressors and promoting wellbeing
- Maintaining vigilance
- Family contributions to safety as success.

Minimising risk and risk avoidance

In adult mental health, safety is concerned with minimising risk – risk avoidance of harm to self or harm to others – and, once stabilised, in avoiding future deterioration of mental health. The way in which safety is addressed in adult mental health practice is through *joint crisis plans* that reduce the likelihood of compulsory detention under the Mental Health Act (1983) (Henderson et al 2004), or from interventions that reduce the likelihood of suicide (Bateman and Fonagy, 2008). The most prominent example of minimising risk and risk avoidance (highlighted by all

participant groups) was mental health crisis and contingency plans which had been carefully constructed with parents and children. Participants felt strongly that the more parents and children were involved, the greater the outcome. Outcomes associated with the development and implementation of these plans included: a reduction in hospital admissions; shorter in-patient stays; quicker recovery times in the acute phase of illness; fewer episodes of self harm and problematic behaviour; and reduced levels of anxiety for parents and children *in* and *out* of crisis.

Interventions targeted at reducing stressors and promoting wellbeing

Continuity in key worker, longer-term support in and out of crisis, and minimal disruption of routines during a crisis (including avoiding hospitalisation of parent), were identified as ways of avoiding or ameliorating crises. Respite from parenting (for parents) and from parent's difficulties (for children) and stepped up contact and support provided from a CMHT Crisis Intervention Team were the two most frequently mentioned additional interventions introduced at times of impending or actual crisis situations. Parenting support interventions helped by decreasing stress and isolation and increasing parenting skills and confidence. This led to improvements in children's behaviour, mental health and general wellbeing, which in turn reduced the impact of parenting on parental mental health. Having an adult to talk to and peer support was particularly helpful for children. CMHTs and voluntary sector agencies using resilience and mental health recovery approaches deployed a range of interventions targeted at promoting individual and family resilience and reducing stressors (Dearden and Becker, 2004; Grant, et al., 2008). These combinations of interventions have the dual focus of lessening the impact of stressors during crises and promoting the mental health and wellbeing of parents and children, which is consistent with public health commentators and studies about service user satisfaction (WHO, 2008), (DH, 2010). But is being risk averse enough? What about the longer term consequences of abuse and neglect for the child? Or, the cumulative prolonged impact of parenting and other stressors on adult mental health and recovery? This will be discussed in *Barriers to success* at the end of this chapter.

Maintaining vigilance

For parents and children who may conceal or minimise their difficulties (as was the case in a number of the case study families) research and practice commentaries highlight the importance of providing a dependable professional relationship (Woodhouse and Pengelly 1991; Brandon et al 2008, 2009; Burton 2009). A small number of professionals from Barnardos Action with Young Carers had made a concerted effort to co-work in a 'team around the child and family' (using the CAF process) to improve communication and to ensure that parents were not able to draw their allocated workers into collusive situations that would result in a loss of focus on the child. For these skilled and experienced practitioners who had got to know families well, it had become possible to understand when important information or serious problems were being concealed by parents and more intrusive measures to protect the child were needed (Burton, 2009). The process and the need to maintain professional vigilance was further supported by case-work supervision from highly experienced, knowledgeable and empathic supervisors (Woodhouse and Pengelly 1991; Brandon et al 2008, 2009; Burton 2009). A parent acknowledged that the CAF process and meetings were challenging and uncomfortable, but was pleased that this was in place as she felt safer in the knowledge that everyone was aware of what everyone else knew.

When there were other family members who were supportive (partners/fathers, parents/grandparents, siblings, aunts and uncles and close friends) important opportunities arose for spotting early signs of deterioration and mobilising support to avoid a crisis, or ameliorate it should it occur. Unfortunately, few families benefitted consistently from this support.

Significant improvements to the social circumstances of case study families were rare. When they did occur, they were extremely beneficial (e.g. re-establishing contact with extended family members; moving to better housing or a safer neighbourhood; the support of a personal assistant) and were associated with improved mental health and decreasing the level of stress in households (SEU, 2004). Tensions arise when the primary focus is about pathology and being risk averse, coupled with limited access or attention to social care and community support interventions that have potential to make fundamental and lasting

differences to the mental health and wellbeing of individuals and families. Safety, then, is necessary, but is alone an *insufficient* condition for success.

WELLBEING AS SUCCESS

Wellbeing is a dynamic state that is enhanced when people can fulfil their personal and social goals. It is understood both in relation to objective measures, such as household income, educational resources and health status, and subjective indicators, such as happiness, perceptions of quality of life and life satisfaction. Evidence suggests that a small improvement in wellbeing can help to decrease some mental health problems and also help people to flourish. Three of the five components of wellbeing will be discussed here: *Connecting with the people around you*, *Keep learning* and *Giving.*

Connecting with the people around you

Gutman et al's (2010) analysis of longitudinal data indicated that positive family relationships were associated with improvements in parents' and children's wellbeing. In Ireland, children's views were sought to inform the development of a set of national child wellbeing indicators. Central to these 8-12 year-old children's views of wellbeing were interpersonal relations with family and friends (including pets), and positive activities or things to do (Sixmith et al, 2007); both of which resonate with what children had to say in this study. A review of the evidence on family breakdown and children's wellbeing (Mooney et al., 2009) found that what seems to be more important to children's subjective wellbeing than family structure is the extent to which parents and children 'get along'. The Children's Society survey of schoolchildren (Rees et al, 2009) found that family conflict had the strongest association with child unhappiness, and a simple measure of how families were getting on was able to explain 20 per cent of the variation in children's subjective wellbeing. Any improvement in the parent–child relationship was of high importance. Parents and children tried hard to keep their families together and make improvements to their relationships with each other. Attempts to reduce family conflict included separating from an abusive partner and attending family therapy to address relationship difficulties between parents and children. Positive or renewed contact with extended family members and friends was also associated with

individual and family wellbeing and these relationships were central to 'what works' for children.

Parental mental health and parent–child relationships improved noticeably when parenting responsibilities were significantly reduced or where parents had regular breaks from parenting, and children had breaks from caring or exposure to their parent's difficulties. A planned 'looked after' service for one child was an important source of support and the value of looked after/respite care has been identified in other research (Aldgate and Bradley 1999; Packman and Hall 1998; Greenfields and Statham 2004). However, it should be noted that improvements in parental mental health did not always mean improvements in parenting, which is consistent with other studies (Falkov, 1999; Cleaver et al. 2012). Neither did they necessarily mean a reduction in the caring responsibilities for young carers.

Keep learning

Learning is closely intertwined with wellbeing for both adults and children. Parents and children were supported to engage in a number of academic and non-academic learning opportunities. The school environment, as a context of learning, has been found to play an important role in children's social, emotional and behavioural wellbeing (Gutman and Feinstein, 2008). The positive association between learning and wellbeing has also been shown to be longitudinal – predicting change from childhood to adolescence. Children's learning and enjoyment in primary school predicts their later wellbeing in secondary school (with some gender differences). Children and their parents had very different experiences of educational professionals and school environments. Head teachers and school staff who adopted a proactive and sensitive approach to supporting children in the context of their family were considered to be major contributors to successful outcomes. However, this support was not as not available to all children and when children moved to secondary schools support in school reduced considerably. Voluntary sector professionals were instrumental in bringing the needs of children and their parents to the attention of schools and encouraging schools to support them in different ways. Children whose difficulties remained hidden for several years (which was the case for some children) and had become entrenched were more difficult to motivate and support. The Manchester *Mental wellbeing of young carers* study

found that participants in the 14–17 year age group (who had been caring for longer periods of time – at least two years; more than ten years in two cases) were less optimistic about the future, had a poorer self view, depleted levels of interest in new things and did not feel as close to other people (Abraham, K, Aldridge, J. 2009).

Giving

Parents and children were interested and enthusiastic about '*giving something back*', both to the agencies that supported them and to other families. Where parents and young people were encouraged to participate in service planning, research and workforce development initiatives, particularly where they were able to see positive tangible outcomes associated with their involvement, this resulted in a strong sense of achievement and confirmation that they had something important and worthwhile to contribute. Similar outcomes were reported through taking part in peer support groups and church and community activities. Being able to give advice and support based on their own experience to others in similar situations, and to receive help in response, helped raise confidence, boost self esteem and reduce isolation.

Parents were happier when they could 'give' back to their family when they were feeling stronger and this was often the case when other aspects of parent's lives improved. Parents were then more available to their children and had more energy and emotional capacity to listen to their problems and help them. Improvements in mental health, making new friends, and getting essential housing repairs completed, were all cited as contributory factors to freeing up parent's capacity to support their children. Young carers were proud of the role they undertook in the family and some viewed caring as a positive contributory factor to their own personal development, helping them to mature and increasing their capacity to cope with challenges in the future.

SATISFACTION AS SUCCESS

Satisfaction is examined in the literature either as part of a general exploration of service user experiences or specifically in studies and surveys seeking children's and parents' views about services. The discussion in this section of the chapter focuses on the sub-theme of *therapeutic relationships. Co-ordinated and inclusive care, understanding mental illness* and *opportunities to have fun* were also identified

as sub-themes in this category of success and they will be discussed later in this chapter under *Inclusion and Effectiveness.*

Parents and children who had established a consistent trusting relationship with a professional were keen to emphasise how these relationships made a fundamental difference to the way that they were leading their lives. In a highly-cited review of service user experience, it was found that by far the largest predictor of outcome was '*the nature of the relationship with their worker'* (Lambert and Barley, 2001). Where satisfaction is expressed in the literature it often centres on the relationship with the worker, the worker's personal characteristics, and the provision of emotional and practical help (Cleaver et al. 2008, Baisow and Hetherington 1998, Spratt and Callan 2004, Dale 2004) and this is consistent with the findings in this study. Parents and children identified a number of personal and professional characteristics that they considered to be central to the successful relationships they described and some consensus was reached about what these were. These are discussed under *Contributions to success* later in the chapter. What was not apparent in the literature is the contribution that parents and children took to enable their relationships with professionals to work so well.

INCLUSION AS SUCCESS

Success in parental mental health and child welfare work can also be detected in its application to social inclusion. The three themes identified in the findings about *Inclusion as success* that will now be discussed are: *The inclusion of gaining service accessibility*; *The inclusion of meaningful participation*; and *Organisation commitment to families*.

<u>The inclusion of gaining service accessibility</u>

Stigma plays an important, but not exclusive, role in determining parents' and children's willingness to approach or engage with services. Many parents, as well as children and young people, mistrust statutory services. This can put children and young people at risk of further problems and sometimes significant harm. Parents in the study were very aware of the stigma associated with parents and families that are not coping, through experience, and they were particularly worried about being

judged negatively, particularly by CSC. Families were less apprehensive about contact with mental health services and the voluntary sector agencies taking part, however, the majority of families were only made aware of voluntary sector support when CMHTs or CSC teams referred them there. The literature about young carers states that the nature of caring is often such that young carers can disappear from the 'normal' social radar to the extent that they become a 'seldom heard' group within the overall population (Aldridge, 2003). Some children also hide their caring role from their peers, as they feel they are at increased risk of bullying if the nature of their parent's disability is known (Dearden et al, 2000). This highlights the importance of doing everything possible to help parents and children feel that they are not stigmatised when seeking help and to make sure that they retain an appropriate degree of control over subsequent stages of the support process. Knowing about promising interventions and approaches to supporting families and protecting children is of little assistance if the family is not known to the agencies with statutory responsibilities.

Where The Assessment Framework for Children in Need (Department of Health (DH) et al 2000) (CAF) was adhered to, there were positive results with some families. However, all too often professionals do not fully engage with the process, or only some engage which reduces the effectiveness of this systemic approach to assessment and support. Research provides mixed messages on parents' and professionals' perceptions of CAF as a route to services (Brandon et al 2006). The CAF worked for the families in this study because the professionals involved recognised the potential it had to offer and put themselves forward to make it work. Parents were more satisfied as communication between different professionals and the family improved and professionals (from all sectors) expressed satisfaction as they were not left alone to cope with 'risky' or 'difficult' situations. Working in this way also provided opportunities to learn from the combined expertise of different professional perspectives. The success here was not about the CAF itself but rather the professionals' commitment to adhering to sound systemic and working together principles that incorporate families as equal contributors.

Skilled and knowledgeable professionals, who were able to accurately identify and match support to the needs and wishes of family members and signpost them to

services that could help, made significant differences to families' lives, despite sometimes only having minimal contact. Statutory sector professionals did not always appreciate the significance of this work due to the short length of their involvement. Staying involved to support a service user through the referral process to engagement increased the take up of services. Help to navigate the complex and separate systems of adult and children's services on behalf of parents and children aided access to services previously out of the family's reach. Flexible delivery of support, for example, holding a CPA or a mental health review in a service users home (when they are agoraphobic), or a CAF review at the school (ensuring teaching staff were present), were all ways of making sure that helpful interventions took place. A flexible approach to re-referral after a person or family have been discharged from a service helped mobilise support early, before difficulties became entrenched.

Relationships that developed through successful assertive outreach resulted in strong therapeutic bonds between family members and the professional. Professionals argued that not working in this way results in important opportunities to intervene being missed. In some cases, safeguarding issues were identified that previous workers had missed because they had withdrawn when initial attempts to engage the family had failed. Professionals in statutory services said they did not have the 'luxury' of being able to spend this amount of time trying to engage individuals and families, although they recognised the need for this.

Two school learning mentors, two teachers and one Connexions worker were cited as professionals who had noticed difficulties and mobilised support for children and their families. This represents a very small proportion of the education professionals in contact with children in the study. Some children's difficulties had remained hidden for very long periods – in some cases years – before they were offered any help. This is consistent with the literature about young carers, which asserts that school rarely provides an environment in which professionals accurately and routinely observe and identify behaviours that may indicate need on the part of the child or young person (Butler et al, 2005). Young carers' research has attributed this to a lack of awareness about the realities of caring on the part of education professionals. Teaching staff supported children to participate at school in a number of ways,

including access to pastoral support at times of stress, and a general willingness to treat the realities of their care-giving role as a legitimate reason on occasions when they are unable to comply with the demands placed on them at school (Eley et al, 2004). A very significant and additional focus for these professionals not mentioned in the literature was on *bridging and attending to the gap between school and home* which involved supporting parents.

The inclusion of achieving meaningful participation

This is the success of those who already have access to services and are included in information and decision making processes over the services that they receive (Corby 1996, Dubrill 2006). Help to understand more about mental illness and child development assisted parents and children to participate more and lead decisions about their care and this was most notable in the development of mental health crisis and contingency plans. Mental health professionals adopted a bio-psycho-social education approach to sharing information with parents about how medication works, i.e. why a 'therapeutic level' has to be reached; why stopping medication abruptly can be detrimental, why drinking alcohol or taking illegal substances at the same time can reduce the effects of medication or cause adverse reactions; and why some medications help some people in some situations and not others. Where professionals and parents were committed to working together to review the effectiveness of medication, sometimes for lengthy periods of time, the rewards included maximisation of treatment outcomes; reduced side effects; improved compliance; and better mental health for longer periods – which was beneficial for parents and children.

Parents and young people were empowered when they led their own care planning process or formally complained about services or incidents that they were unhappy with. Whilst it was only true for one family, employing a personal assistant using Direct Payments resulted in positive outcomes for everyone in that family. This could be because the take up of Direct Payments and personal budgets in adult mental health services is far lower than other adult service groups.

Organisation commitment to families

At the time the research took place, both Liverpool and Lewisham had volunteered to be implementation sites for the SCIE *Think child, think parent, think* family guidance (SCIE, 2009). Both have a track record of innovation in this area of practice, but Liverpool had been much more active in recent years and had a multi-agency improvement plan agreed. There was a palpable sense of pride emanating from parents, children and professionals from Liverpool who had taken part in this initiative. There were six factors or processes that appeared to support this sustained commitment to change in Liverpool:

1. **A group of interested and committed professionals from different agencies coming together to affect change** – because services are separate and fragmented, this multi-agency approach is important if the needs of all family members are to be addressed.
2. **Securing senior management involvement in the group or their '*sign up*' to improvement work** - senior management involvement is necessary to ensure that any improvements are put firmly on agency improvement agendas, to mobilise resources and manage implementation and evaluation in collaboration with other managers.
3. **A commitment to evidence-based decision making (drawing on the best available evidence from research, practice, and service user and carer expertise)** – a number of the developments in both sites have been preceded and support by research into local need and developments such as Building Bridges have been independently evaluated and reviewed. Both sites volunteered to be implementation sites for national guidance (Diggins, 2009) and their experiences were evaluated and used to update the guidance (SCIE, 2012) – see also 4 below.
4. **A strong commitment to co-production and participation from the outset ensuring that families are involved and supported in all aspects of decision making and development** – this was firmly developed in Liverpool and part of mainstream service development practice and was facilitated by Barnardos Action with Young Carers project. It was much less developed in Lewisham at the time of the research.

5. **Being willing to tackle the '*too difficult to handle'* issues that had previously been set aside** - taking on some of the issues that most affected families and challenged staff helped increase confidence in the work of this group when their efforts were successful.
6. **Recording and sharing 'what works' locally and nationally** – by: communicating their successes via publications' at local and national events; contributing their expertise to new policy developments; delivering training and consultancy across the country; and formal evaluation of their work. Thus contributing further to the evidence base about *what works*.

This 'top down bottom up' approach to change has resulted in significant and sustained changes in Liverpool that have received national recognition (SCIE, 2012). Their success has helped them to secure funding from central government and others which has helped to maintain the momentum of their progress and to keep services such as Barnardos Action with Young Carers going (funded). The senior management group involved in this work are clear that the cornerstone of their success is the combined sum and nature of the people involved, and that the work undertaken by these people would be seen by others as 'over and above' what their organisation requires of their substantive posts. Therefore, if members of the group leave, the sustainability of the group and the work becomes threatened. In recognition of this, the group aim to *mainstream* the processes and resources that they develop to increase their survival rate – thereby making them part of everyday practice rather than an 'add on'.

EFFECTIVENESS AS SUCCESS

The *Literature* chapter in this thesis discusses a range of interventions and professional approaches that, because of their evidence base, have a reasonable chance of achieving some progress in parental mental health and child welfare work. The same methods and interventions surface in different combinations in the findings of this study. Their applicability to parental mental health and child welfare work will now be discussed.

The findings are consistent with the idea that families may need a multi-dimensional approach and range of interventions over a longer period of time to promote adult and child resilience (Dearden and Becker, 2004; Grant, et al., 2008). Public health commentators agree that multi-faceted and multi-level interventions, which stimulate resilience as well as address mental ill-health, are needed in order to improve outcomes for families affected by parental mental health and multiple disadvantages (Aked, et. al, 2008; Foresight, 2008; Bartley, 2006). A pre-requisite to this way of working is that practitioners and services need to understand the factors that can promote resilience and how adults and children can make favourable progress in unfavourable circumstances (Cleaver, 2012, Falkov, 2013). Knowing too the range of approaches that can help to deliver this model of practice intervention and being open to offering support in non-traditional ways was crucial to maximising children's resilience and parents' mental health recovery; for example, encouraging parents and children to participate in service development and providing opportunities for respite and relaxation. Applying a strengths and resilience-led approach helped to engender optimism and commitment in family members and in other professionals.

In regard to individual approaches or interventions, apart from the consistent conclusion about the centrality of the professional relationship, no one service approach or method has yet been robustly evaluated as effective with complex families where there is evidence of maltreatment, or where maltreatment is likely unless effective services are provided. Success that is related to the establishment of a therapeutic relationship between a professional and a service user or family is discussed under *Satisfaction* above.

<u>Interventions that contribute to success</u>

Interventions to improve mental health, particularly psychiatric medication, were thought by professionals and children to be very important and were associated with a number of positive outcomes for parents, children and the whole family. However, tensions arise from this, as whilst the majority of parents could see that taking medication helped, it did not provide anything like the relief they hoped it would. The requirement for most of the parents to keep taking medication as a prophylactic to prevent breakthrough symptoms, and the attending adverse affects associated with some medications, were sometimes too difficult to bear. Particularly when they

realised that the need for treatment might be significantly reduced or stopped if improvements could be made in other areas of their lives (e.g. poor housing, poverty, isolation). So whilst the aim to promote mental health in this way is entirely laudable and commendable, it is not without its costs.

A range of interventions targeted to *promote resilience and reduce stressors* identified in the findings are consistent with research evidence. For example, young carers interventions, including peer support, respite from caring opportunities, and the availability of a trusted adult to talk to and help with school transitions (Dearden and Becker, 2004; Grant, et al., 2008). Young carers' needs legitimately include the need to socialise with peers, including those of their own age, and to gain respite from the caring role without guilt or fear. Support projects for young carers provide a valuable resource for achieving this where 'normal' social networks are either damaged or non-existent (Becker, 2005; Goodwood et al, 2002). For young carers these opportunities have been shown to reduce the physical and emotional stresses of caring, and thus potentially enhance young carers' ability to improve educational achievement. (Butler, 2005; Aldridge et al, 2003). Taking part in a young carer's assessment and being acknowledged as a young carer was an important way of helping to validate and contextualise young people's experiences. This is consistent with the literature on young carers, which purports that the needs of young carers could often be better met by validating their input, concerns and skills (Roberts et al, 2008 (SCIE). See Appendix 6 for an example of what one young carer had to say about her experience.

Family resilience is another level of resilience related to complex relationships and environmental factors. This can be generally defined as the ability of a family to respond positively to an adverse situation and emerge from the situation feeling strengthened, more resourceful, and more confident than their prior state. Having a break from, or reducing exposure to, parenting (for parents); from a parent's difficulties (for children); or from caring (for young carers), reduced family conflict and tension and led to improvements in family relationships. The value of this type of looked after/respite care has been corroborated by research (Aldgate and Bradley 1999; Packman and Hall 1998; Greenfields and Statham 2004).

The concept of self-efficacy and its association with successful outcomes and learning from success is central to this study. Performing a task successfully strengthens our sense of self-efficacy, whilst failing to deal with a task can undermine or weaken self-efficacy (Bandura 1994). Professionals who were able to '*listen without judgement'* (Canvin, et al 2009) and listen to parents and children's ideas about what they thought would work were able, as a result, to identify the significant strengths in families that went under-recognised by other services. Opportunities were then provided for parents and children to build on their strengths (e.g. a supported adult education class for a parent and a leadership course for a young person). .

Social modelling is achieved by seeing people similar to one self succeed through sustained effort, which raises observers' belief that they too possess the capabilities to master comparable activities to success (Bandura, 1994). Spending time with other parents or young people with similar experiences; hearing their stories and what they found worked for them, helped parents and children to feel less isolated and more able to try new strategies for change. Verbal encouragement – *social persuasion* from support workers from all agencies, helped parents and children to overcome self-doubt and come to believe that they had the capabilities and skills to succeed. For example, helping a parent to leave the house, take their children to the park, or join a women's group (Bandura, 1994). Utilising *psychological responses* is about learning how to minimise stress and elevate mood when facing difficult or challenging tasks, which can help people to improve their sense of self-efficacy (Bandura, 1994). Psycho-social education helped parents and children to reflect on their experiences and identify the warning signs that things are not going well, and what will prevent things getting worse; as well as what they need to do to not only cope with their circumstances but to recover and live well. Examples of this include counselling, family therapy and inclusive mental health crisis and contingency planning (Kuipers, 2006).

Public health literature and research on resilience-led approaches supports targeted interventions that aim to intervene early, in order to prevent the cycle of impacts occurring across the lifespan (childhood to adulthood); between parents and children; and across generations (WHO, 2008; Beardslee, et. al, 2003; DH, 2010).

Identifying, assessing and supporting young carers as soon as possible, supporting families through the transition from primary to secondary school, and helping children to understand they were not responsible for their parent's difficulties were all ways that professionals (particularly voluntary sector agencies) tried to increase opportunities for change.

Families struggled with low income, unemployment and poor housing. Attempts to alleviate these fundamental areas of their lives were met by a multitude of barriers. Where there were breakthroughs, these were mostly attributable to the sheer determination and perseverance of parents, and advocacy and support from professionals, who tried to reason with gatekeepers and navigate the un-family friendly eligibility thresholds that operate in housing and other social care providers. Families were thankful for the support they received but felt that the underlying reasons for their difficulties were paid little attention or resources.

Service models that contribute to success

Berry et al (2006) and Tunstill et al (2006) found that neighbourhood family centres combining drop-in support and parenting training with 'targeted' outreach services can be particularly successful in working collaboratively with some families with very complex problems. The services they reviewed offered the same range of interventions, i.e. practical assistance, educative and therapeutic group work for parents and children, and relationship-based casework, that are offered by Liverpool Action with Young Carers and Lewisham Building Bridges. The services were staffed by professionals who were knowledgeable about the needs and preferences of parents and children and experience of the tasks involved in constructing local service networks and skills in joint working. This was also the case for the projects in Lewisham and Liverpool. Berry et al (2006) and Tunstill et al (2006) found these centres to be 'well positioned to 'hold the ring' between family members' support and protection needs', in line with the (mainly descriptive) evaluations, going back many years, of the work of Family Service Units, which combined a centre base with intensive outreach work. More recent examples within the voluntary sector are the work of Kids Company (Gaskell 2008) and Action for Children (Tunstill and Blewett 2009) (in Thoburn et al 2000) which provide **'**as long as needed' key worker outreach

services with a drop-in facility. In these service models, parents and children form a relationship with the centre as a whole, which can facilitate the provision of a cost-effective 'episodic' service. This type of service can be particularly appropriate for families with long-term and multiple problems, and also those with a 'single issue' such a recurring mental illness, or parents or children with a long-term disability or health condition (Thoburn et al 2000).

CONTRIBUTIONS TO SUCCESS

The findings demonstrate that parents, children and professionals all have important contributions to make, but it is when their contributions (perspectives, resources and determination) combine that success is more likely to be achieved.

Parents, children and other family member contributions

Positive and supportive contributions from other family members, extended family members, friends and the church were crucial to the survival of some families. Support from these sources included: reassurance; shared parenting; help with childcare; financial support; help in a crisis; friendship and love and reassurance. Children in particular valued the contact and comfort they drew from relationships with family members who lived close by. Few families though benefitted from this kind of support. Despite the significant contribution made by extended family members and other close supporters, they received little attention from professionals in regard to including them in assessment and care planning processes or in regard to an assessment of their needs.

Practitioners who commit themselves to families

Professionals who were identified by parents, children and other professionals as making very significant contributions to success shared a number of qualities. The driving force for these professionals was their commitment to families and their determination to take responsibility for making their contribution count – for making a difference in their lives – even when others had failed before them. For these professionals, commitment was not an abstract notion. Its basis was the relationship they developed with the parents and children with whom they worked; their ability to identify with the families and their attempts to cope with their difficulties. They recognised that just as they had needed and received help in their

own lives, so did others. They clearly understood the inequality that exists in many families where social deprivation and other stressors prevent parents looking after and providing for their children in the way that they want to, and in ways that other people automatically have the resources to do. By getting to know families, and learning from their own experiences and the experience of working with many parents and children, they were able to view what was happening through the latter's perspectives.

A number of professionals succeeded in helping parents and children whom others had previously failed to assist. What these professionals had in common was that their starting point appeared to be the family's circumstances and perspectives and they did not get bogged down at the outset by the confines of formal organisational structures or professional boundaries as earlier chapters indicated in this thesis can lead to a '*sorry, but we can't help you*' response. Communicating on a personal level and without judgment; recognising the complexities of parents, children and families lives; as well as their resources; and attempting to change their situations and to protect their dignity, were all attributes associated with success. The professional approach started from a standpoint of understanding why families might be sceptical about receiving help or engaging with interventions, followed by taking on the task of proving, over time, that they could in fact be depended upon to try and help in a manner which was acceptable for the family. In doing so, they provided a service that was educative, supportive and timely and included practical help from the start. Parents and children said they value professionals:

- who are genuinely interested in them, care about them and not just about their problems
- are flexible and willing to work outside of what would be considered normative professional boundaries (e.g. hold a review meeting at home; phone them at the weekend)
- offer them enough time to talk, get to know them well and can then see things from their perspective
- are reliable, do what they say they are going to and are available when they are needed

- don’t give up or forget them even when parents/children/families turn them away
- are knowledgeable and skilled in ways that can help them with their difficulties (Katz et al, 2007)
- can provide opportunities otherwise out of their reach
- are fair, honest and are prepared to challenge them (this was only parents and children who thought professionals had taken the time to get to know them well) as well as offer support in a non-judgmental way
- stay with them in and out of crisis and overtime
- are willing to tackle and work with other agencies and bureaucratic systems (service eligibility thresholds etc.) on their behalf
- (for parents) continue to think about and support their children, when they cannot
- help them to reflect on and address their difficulties by sharing information
- persevere, don’t give up and are willing to go the extra mile.

These characteristics were present in different combinations in the professionals that parents, children and other professionals cited as making a very significant contribution to success. Professionals described a number of sources that they drew upon to support their practice. Some professionals drew on their own family experiences of mental health to help them to understand what families were experiencing; others attributed their actions to professional training and professional supervision (Katz et al., 2007), which were the most frequently mentioned sources of professional support that enabled professionals to practise in the ways that families preferred. For the voluntary sector professionals, the ethos and culture of their organisations allowed them to do things that were not similarly supported in the statutory agencies (e.g. assertive outreach and the length of time they were able to spend with clients).

BARRIERS TO SUCCESS

Problems with assessment and accessing services

My professional knowledge and experience helped me in my role as researcher to gain a reasonable assessment and understanding of family history and current

circumstances for each of the 12 case study families. What became clear during the process of interviewing parents, children, and professionals, and reviewing case files, was that individuals had differential access to information and perspectives about their families or the families they were working with.

The child's voice and perspective was largely missing from all of the statutory agency case files. Significant family members were not consulted as part of the assessment process (such as adult partner/carers/fathers, other children in the family, extended family members including grandparents, aunts and uncles). In the few cases where there had been contact, it was at the point of crisis itself, after family members alerted services of difficulties. Gaining children's or other relatives' views can be complicated if parents do not give permission, though there was little evidence that the professionals (with the exception of voluntary sector staff) had tried to meaningfully include children in assessments about them or their parents. There was an over-reliance by the majority of professionals on what parents had to say about their children's difficulties; which meant, for those families who were isolated, there was no other adult aware of what was going on at home for these children. This is problematic because the findings highlight a marked difference between what parents and children in the same families had to say about the severity and longevity of negative impacts on children's lives, particularly the emotional impact. This was complicated by a further theme in the findings; namely that professionals did not have enough contact with children or knew enough about child development and mental health to accurately identify the true extent of children's distress (Akister, 2011). Gaps were also found in multi-agency communication and the assimilation of different professionals' perspectives, as professionals did not routinely and proactively take steps to identify and communicate with other professionals supporting the family – at the time of taking on a case or afterwards.

Professionals therefore gathered only partial information, and efforts to assimilate and make sense of multi-agency perspectives and past and present circumstances was mostly absent in case files. Gaps in information make it difficult to assess current and future safeguarding, as well as to achieve sound and cost-effective decisions about duration and intensity of the services needed to prevent abuse and promote wellbeing. Whilst these gaps in basic assessment might be hard to believe,

they do exist, and are corroborated to an extent in the literature (see *Chapter 3*). When challenged about these omissions, professionals, whilst apologetic, felt safe but not comfortable in the belief that this was symptomatic of a flawed system, rather than them colluding with a culture that focuses on immediate risk and short-term interventions. The file reviews identified psychiatrists and mental health professionals as the best at taking psycho-social histories.

A further omission found in the majority of case study families was that there was no CSC oversight and periodic reassessment of cases in the light of challenging circumstances and new information; despite research demonstrating that this is needed to assess changing circumstances and avoid the 'start again' approach that the majority of families experienced from CSC (Brandon et al 2008; Burton 2009).

Missed opportunities for early intervention and prevention

Some professionals lacked adequate knowledge about child development and child mental health to accurately identify the true extent of children's mental ill-health or when it reaches a level that requires professional investigation or treatment. Children had been referred to CAMHS services for support but usually only following a crisis (e.g. a response to threats of or actual self harm, eating disorder, serious isolation and withdrawal) and in all of these cases CAMHS involvement generally ceased following crisis resolution. Assessment and responses to children's emotional difficulties did not include enough attention to the impact over time of continuous or frequent intermittent exposure to parental difficulties on children's mental health and wellbeing. Schools did not always treat parental concerns about their children seriously and some professionals (from all agencies) were open about how their lack of confidence got in the way of assessing and identifying children's difficulties and referring them for support (Tompsett et al, 2009).

Paying attention to adults as individuals

The findings demonstrate that adult services are paying more attention to the needs of adults as parents; however, attention paid to the needs of adults as individuals and the belief in mental health recovery is less apparent, particularly in regard to employment. Parents experienced both internal and external pressure to seek work. This was in conflict with very strong fears, sometimes based on previous experience,

that the responsibilities and demands of a job would jeopardise their mental health, and, ultimately, the care of their children. These feelings were further exacerbated by the reality that finding a job with a salary that will meet the needs of the whole family and pay for child care (eleven out of twelve parents were single parents) was extremely unlikely. Generally parents had low expectations of what they could achieve or in a few cases (2) unrealistically high expectations (sometimes symptomatic of their illness), leaving them consistently dissatisfied with this important aspect of their lives. In spite of these conflicting feelings, a number of parents wanted to work towards meaningful occupation; which may or may not be paid work. Practitioners, too, had low expectations of what parents could achieve (SEU, 2003) and parents complained that support that was offered did not take account of their strengths (previous knowledge and skills) and was frequently 'one size fits all', preventing them from building on any successes. What really appeared to be missing is the belief in mental health recovery.

Professional and practice dilemmas

Professionals involved in the research were committed to their profession and talked about how their jobs always required 100 per cent effort from them, and usually much more. Families are currently coming to services with increasingly complex and more enduring difficulties (e.g. unemployment, substance misuse, experience of violence, homelessness). In parallel, both of the voluntary sector projects taking part in this study have faced repeated threats of closure due to the short-term nature of funding and persistent threats of further cuts, whilst demand for services increases. Professionals talked about the impact of the cuts on services on what can be offered to families. As a consequence, services are asked to stretch to reach a wider population, resulting in a broader but greatly watered-down impact on families; where essential services go missing from the system of support, thus making the whole support package less effective. There was a persistent frustration for professionals, particularly in the statutory sector, about wanting and having undergone training to help those in need, but rarely being granted the conditions which would make successful helping possible.

CONCEPTUALING AND EVALUATING SUCCESS

Success in parental mental health work is seldom reported and rarely appears as the subject of empirical research. This part of the discussion will refer to the *Literature* and *Methodology in action* chapters about the difficulties in identifying success and the contribution that focusing on success and utilising mental health promotion can make to improving our understanding about what works in parental mental health and child welfare work.

Finding success

Some professionals found it hard to conceptualise what success looks like in parental mental health and child welfare work, while others were sceptical that parents and children would say they had experienced successful outcomes that were in some part due to their agency's intervention. This was particularly so in the statutory sector agencies in the first research site, where recruitment was extremely slow and arduous. In contrast, recruitment in the second research site happened very quickly. I believe a number of factors contributed to these very different response rates. The first research site had experienced a small number of recent serious case reviews in children's services that had involved parental mental health issues, and staff were feeling particularly sensitive to the outcomes of these. This had led to a defensive approach to this study, as senior managers wanted to protect their staff from further investigation and potential criticism, and assumed that this study too would have only negative findings. There was also a general feeling in both statutory agencies that despite some considerable effort (development of inter-agency protocols, multi-agency training), they felt they had a lot more to do to get things 'right' for families that straddled the interface between services. Of those families that were identified by senior managers but did not take part, this was not because the families rejected the invitation, but because I was told by key workers they wanted to '*protect [their] clients from undue stress*' or because in their opinion their clients were '*not suitable and would not be able to give [me] what [I] needed*'. In contrast staff at the second research site (Liverpool), were confident they could identify and recruit the remaining nine case studies and went out of their way, despite busy workloads, to facilitate the recruitment process. Staff there worked very hard as part of an inter-agency senior management group to make significant changes in Liverpool and were very proud of the outcomes that had been achieved

for families, and their contribution to these developments. Like Lewisham, they appreciated there was still a lot more to do, but were confident that they had made a good start. A further contributory factor was that this project was very good at supporting parents and children to participate in developments to the project, elsewhere in Liverpool and nationally. The only other organisation directly involved in Liverpool was the mental health trust. They did not have to act as gatekeepers to the research but staff from the CMHTs who were involved in supporting the case study families were invited to take part. The response to invitations to take part from key workers in the CMHTs was mixed. Very few agreed to take part (3) and the remaining six, mostly psychiatrists, did not.

It can be seen from the findings that whilst adult and children's services workers are now more readily including a '*think family'* perspective in their work, the policy and theoretical imperatives driving service delivery are still divided between being either adult or child outcome focused. In the recruitment phase of the study, it was difficult for professionals to see through the family's eyes what they were experiencing and what it looked liked when things worked out well. Professionals were easily sidetracked into discussing problems with service pressures, decreasing resources, bureaucratic pressures, and what could not be done. In contrast, Lewisham Building Bridges and Action with Young Carers both employed a 'whole family approach'; however, neither had a significant remit or expertise in adult or child mental health. As we have seen earlier in this chapter, organisations and practitioners are charged with the responsibility of *working together* to include attention to the individual and the family, but their primary goals are different, making it hard to prioritise what should happen at the interface between their services, to ensure a focus on the safety and wellbeing of individuals and whole families. As highlighted in the *Context* chapter, the 'add on' policy developments that aim to alleviate the problems caused (to the tax payer and the public) by 'families at risk', 'complex families' and 'troubled families' have done little to affect changes to adult and children's service delivery systems. By focusing on very specific groups of families in this way, the majority of families in need are excluded from support and the benefits of new resources. Similarly, whilst the focus on identifying young carers and their needs is increasing (and is long overdue), the focus on this group may draw resources and attention

away from other children in the family who are also affected and in need of support but do not meet the criteria of young carer.

There are, then, a number of interrelated factors that can make it difficult to conceptualise, identify, work towards and evaluate success. These include: a preoccupation with avoiding failure rather than focusing on success; being conditioned to learn from mistakes and not success; practitioners doubting their contribution to success; and a preoccupation that more could be done but resources do not permit this, and so there is nothing to be done. In addition, there are opposing definitions of success, which begs the question – whose success is it anyway? Interventions are legalistic with little discretion for experienced practitioners, and practice is tightly prescribed by guidance and monitored closely by local and national sources of inspection and scrutiny. In this environment, practitioners can become disillusioned, disengaged or subversive. So how can we arrive at a shared perspective that everyone, regardless of their position in the family, can benefit from, and where every professional, regardless of their discipline and client focus, can opt to understand individual and family difficulties, understand and identify success, know how to help families, go about achieving this and evaluate outcomes?

<u>What does focusing on success offer to our understanding of parental mental health and child welfare work</u>

This study has focused on success and learning from it. The findings demonstrate that understanding and knowing what success looks like can be difficult, and competing priorities in the context of ever-reducing resources can impact on the ability of different services and practitioners' ability to support individuals and families. However, by focusing on success, we can see that some organisations and some professionals manage to achieve this very well, in collaboration with families, despite the barriers uncovered. This suggests that more families may benefit if we can learn from some of the successes of these families and the people that have supported them.

The contribution of a range of theoretical frameworks to our understanding, practise and evaluation of parental mental health and child welfare work were reviewed in Chapter 4. The findings demonstrate that definitions of success, contributions to

success, and barriers to success are affected and influenced by: individuals, the family, the community, the environment, social, biological and psychological factors, and the contributions of law, policy, and health and social care organisations. We can see in the findings and in other research that the inequalities and deprivation experienced by some families can transcend from childhood to adulthood and across generations, which highlights the public health challenges that arise if the cycle of deprivation is not addressed sufficiently. This is very well illustrated by the 'stop and start' nature of services that retain a primary focus on immediate safety and are risk-averse, and the length of time that some children are left in distress before their difficulties are recognised.

Mental health promotion is proposed here as an all-encompassing approach that attends to all of the areas of importance uncovered in this research. It works at three levels, and each level is relevant to the whole population: individuals at risk, vulnerable groups, and people with mental health problems. It links to psycho-social wellbeing, as well as to the wider concepts of social inclusion, inequality, discrimination and its prevention, citizenship, and social capital. It is applicable to all ages and client groups, and therefore all professional groupings; which, if applied systematically, could encourage the shared perspective that is often missing in existing policy and multi-agency practice. It has a strong evidence base and evaluation framework.

Mental health promotion includes both any actions to enhance the mental wellbeing of individuals (of any age), families, organisations and communities; and a set of principles which recognise that how people (adults and children) feel is not an abstract and elusive concept, but has a significant influence on health (Friedli 2000). It is interested in processes as well as outcomes, and in what participants feel about the interventions that they receive. It adopts the psycho-social definition of mental health as mental wellbeing rather than the medically-orientated definition of mental health as the absence of mental illness or disease (Tudor, 1996). It acknowledges that how people feel about an intervention may be just as significant as clinical indicators of impact, and that the former will also influence the latter. All of these elements can be found in the findings and components of success identified in this study. Mental health promotion has the additional advantage of an established

evidence base. This has the further potential of providing an alternative framework for interpreting and delivering messages from research into practice, which has been a major objective in this study.

CHAPTER 10 – CONCLUSIONS

INTRODUCTION

This final chapter re-examines the reasons for undertaking the study and reflects on the main questions the research has asked. The findings are reviewed and original contributions to knowledge are discussed, in conjunction with the implications for practice. I will also reflect on what I have learned personally from the process and outcomes of this thesis. The limitations of the study are considered and desirable future research is suggested.

THE REASONS FOR UNDERTAKING THE STUDY

The literature about parental mental and child welfare spans several decades. Most studies are concerned with the potential adverse impacts of parental mental illness on parenting, on child development, risks to safety and at the extreme end, fatal child abuse (Brandon, 2008, Cleaver et al,1999, Gopfert, et al., 2004, Tunnard, 2004). In contrast there has been little research about how parents and their children can be supported successfully. Research recommendations largely focus on making improvements in interagency practice and staff knowledge, skills and attitudes.

Families with complex needs have described the hopelessness they feel when faced with multiple difficulties, such as illness, poverty, chronic unemployment, violence, disability and immigration and for whom survival is a difficult task. They have also described the barriers they experience trying to get support for themselves and their families. Meeting eligibility criteria for services is difficult. Criteria are either set too high or do not take into account the interplay of difficulties within the family. As a consequence families stop trying to get help or find themselves having to exaggerate their 'failures' to get support (Rosenfeld et al, 1993). Professionals have been criticised for focusing too much on pathology and weaknesses in parenting, undervaluing strengths and not taking seriously the service user's own views of resources needs (Hugman et al, 1993).

This area of practice can be challenging, emotive and open to multiple sources of criticism. Some families require the expertise of a number of different professionals to come together to assess and provide support for individuals as well as the whole

family. Professionals and researchers have identified a number of barriers that get in the way of holistic and integrated professional practice, as outlined above. Consequently professionals may be reluctant to work outside of what they see as their professional boundaries (SCIE 2009). This can mean that some of the family's needs may be overlooked, even though they are already in contact with services. Opportunities for preventing problems from arising in the future may also be missed. Breaking down these professional barriers is as important as addressing the stigma that exists in accessing services. It has become custom and practice to talk about barriers to successful practice rather than exploring what happens when families are supported successfully.

A succession of schemes and incentives were introduced by the UK government and SCIE to promote what has been variously called collaborative, joint, integrated and partnership working between health and social care, outlined in the *Context* chapter (Diggins, M, 2009); (SCIE, 2012). Some initiatives have been more successful than others, but generally coverage has been patchy and slow and sustainability a chronic problem (SCIE, 2013).

Based on my professional experience, I was convinced before embarking on this study that despite the very real stigma and barriers that exist for families seeking help, that some professionals and families do manage to overcome or side-step the barriers that others do not and families are supported successfully as a result. Therefore the first objective of this research was to find out what could be learned from these families and practitioners where this was the case.

I was also familiar with how professional practice is driven by policy imperatives and theoretical processes that differ by service and discipline and how harnessing the best of what each has to offer is complex. Hence the second objective of the study was to explore the contributions of different theoretical frameworks to our understanding of what works in parental mental health and child welfare work.

THE RESEARCH QUESTIONS

From the outset of the research people wanted to know what did I mean by success, and did I have a definition for what I was looking for. Discussions about success at this stage were problematic as I was looking for different perspectives about success but I appreciated that there needed to be a starting point. In response as part of the review of the literature about parental mental health and child welfare I put together a '*research working definition of success'* (Appendix 5) drawn from what research, policy and law had to say about successful practice. This provided a baseline or starting point for the research. In my early contact with gatekeepers to the research I experienced similar responses and in this case I amended the language used in recruitment information and gave very brief examples, of situations that families might consider to be successful and this helped. These responses highlight how difficult it was for professionals who spend their working lives trying to support individuals and families towards successful outcomes, to describe what success actually looks like when it occurs. Therefore finding a question that was immediately clear to everyone - '*says what it does on the tin*' was not easy. The research aimed to find answers to the following questions:

1. How do the key stakeholders define success?
2. What tangible, sustainable outcomes do different key stakeholders associate with success?
3. How do the stakeholders describe their role in achieving successful outcomes?
4. How do the different stakeholders describe other people's roles in achieving successful outcomes?
5. What do stakeholder see as the major opportunities in achieving success?

All of the participants I spoke to liked talking about success but they also wanted to talk about the barriers they encountered on the pathway to success. Parents wanted to tell their whole story as it was important to them that I knew the context of their experiences, as only then would I be able to appreciate the significance of the successful situations they described. The interviews and focus groups were semi-structured allowing for themes that were important to participants, such as barriers, to emerge.

THE METHODOLOGY AND METHODS USED IN THE STUDY

This study is a *qualitative* research study using an *interpretative* approach. Data to explore the issues was obtained using a *Multiple embedded case study* methodology (Yin, 2003). A multiple embedded case study methodology was chosen because it is ideally suited to detailed, in-depth data collection involving multiple sources of information.

It is an *exploratory* case study as it is the first ever study to explore *success* with this specific population. It covers a diverse population, including different family members from different cultural and ethnic backgrounds; parents with different mental health diagnoses; and statutory and voluntary sector agencies. It has been important to cover diversity in this case, in terms of uncovering different opinions of success both in outcomes and processes rather than to ensure statistical representation.

Criterion purposeful sampling was used to recruit 12 information rich cases for in depth study from two research sites. Data collection was undertaken in three stages, as described in the methodology chapter, using individual semi structured interviews, case file material, and focus groups in which emerging findings were discussed. 50 participants took part in the first phase of the research (parents, children and professionals from the 12 case studies) 25 case files were reviewed in the second phase and 25 participants in total took part in the three focus groups in the third and last phase.

Thematic analysis was the method used for data analysis. This was a way of identifying, analyzing and reporting patterns within data rich in detail and searching for themes across the entire data set (Braun and Clarke 2006). The *Nvivo* computer software package was employed as a way to respond to the large quantities of data the study had yielded.

Gathering different perspectives enabled the gaps in communication to surface between: different family members; service users and service providers' and different agencies. There were also examples of consensus between the different participant

groups most notably in regard to the centrality of wellbeing in all of the participant examples of success. Investigating different perspectives in different ways (individual interviews, file reviews, focus groups) allowed for these differences and mergers of opinion to be identified. There were further examples of themes that only surfaced as a response to one method of enquiry (e.g. the case file reviews identified problems with agency assessment and recording processes not highlighted elsewhere in the data). Using a holistic method of enquiry enabled me to study the relationships and social processes in the detail needed rather than restricting attention to the outcomes from these.

What I would do differently if I had to do the study again would be to refine the language earlier on in relation to success and be open to the possibility that asking services and practitioners to talk about their practice may be met with a defensive approach to taking part.

THE MAIN FINDINGS OF THE RESEARCH

The first finding is that success in parental mental health and child welfare work does exist and is recognised as such by the key actors. Secondly, it depends on a number of interconnected and interrelated components. Thirdly parents, children and professionals share a great deal in common in regard to what they say *works*, what gets in the way, and what helps to achieve successful outcomes for whole families.

Contributions and facilitators of success

Parents demonstrated great determination and courage when they: fought to get their children's needs addressed.

Parents said their greatest achievement was keeping their families together despite great adversity.

Parents used the knowledge and skills gained in psycho-social casework, peer support and family therapy to improve their understanding of mental illness and child development and used this to reflect on their parenting and other aspects of their lives and make changes.

Children were extremely loyal to their parents and fiercely protective of them, this and the positive attitude that most young carers adopted, helped children to understand their situation more readily and as a number of children said '*just get on with it*'.

Some young carers viewed their caring role and responsibilities as a positive contributory factor to their own personal development helping them to mature and increasing their capacity to cope with challenges in the future.

Emotional and practical support provided by extended family members and friends that live close by provided a crucial contribution to promoting safety and wellbeing for the families who benefitted from this.

Parents and children are clear and unanimous about the personal and professional characteristics that they associate with best professional practice, and many professionals agree

Successful practice was underpinned by a professional's ability to: identify with the family's situation and their attempts to cope with their difficulties; start from a standpoint of understanding why families might be sceptical about receiving help or engaging with interventions; take on the task of proving to families over time, that they can be depended upon to try their best to help in a manner which is acceptable for the family.

Professional practice was best supported when organisations allowed and encouraged professionals to go at the pace of the family; to be flexible and stay involved for the long-term if needed.

Regular high quality professional supervision; learning from experience (professional and personal); hearing about what works from service user perspectives; and keeping up to date with new developments and messages from research, were highlighted as important contributions to professional practice.

Safety as success

Carefully constructed mental health crisis and contingency plans that were developed in collaboration with parents and children were associated with: a reduction in hospital admissions; shorter in-patient stays; quicker recovery times in the acute phase of illness; fewer episodes of self harm and problematic parental behaviour; and reduced levels of anxiety for parents and children *in* and *out* of crisis.

Effective collaboration between agencies and the family was successfully achieved when professionals were committed to *working together* and went out of their way to ensure that it happened. This was associated with high levels of satisfaction for professionals.

Parents felt safer and more satisfied when professionals worked well together and said that the CAF process helped to make this happen and made sure that "*everyone knew what everyone else knew*".

Respite from parenting (for parents) and from parent's difficulties (for children) and stepped up contact and support provided by a CMHT Crisis Intervention Team were the two most frequently mentioned additional and successful interventions mobilised at times of impending or actual crisis.

Improvements to social circumstances were rare, but when it did occur it was extremely beneficial.

When there are other family members involved important opportunities arise for spotting early signs of mental health deterioration; and mobilising support to avoid or ameliorate a crisis. Few families though benefitted from this support.

Effectiveness

When parents and CMHT staff worked together to try to optimise the effects of medication, they experienced a range of positive outcomes including: greater

compliance with treatment; longer episodes of good mental health' and fewer admissions to hospital.

Parental mental health improved noticeably when parenting responsibilities were significantly reduced or they received help with childcare.

Opportunities to have fun, learn new things and have a break were all associated with high levels of service user satisfaction and helped to boost individual and family resilience.

Parents and children believed that if services could pay more attention to and target support at the issues underlying their difficulties (e.g. poverty, poor or inadequate housing, school exclusion, bullying, racial discrimination) as opposed to treating the symptoms of their difficulties, this would result in greater and more sustainable outcomes

Barriers to success

Year on year financial cuts, coinciding with increased demand for services has led to service eligibility being set very high that does not take account of the combined needs of different family members. Funding cuts have led to greatly watered down service provision.

Extended family members were not routinely contacted, supported or involved in assessment and care planning processes by any of the agencies involved in the study. Neither did contacting, helping to develop and supporting relationships within the wider family appear as a safeguarding or wellbeing goal.

Professionals were not always aware of, or took steps to find out who else was working with the family.

There was a stark omission in statutory service case files of conversations with children about their how they were feeling and how they were coping, records instead were about what the parent had to say about their child.

All of the agency case files had gaps in information about: the assessment and activities of other agencies and there was very little historical information about the family (with the exception of CMHT files who were the best at taking comprehensive case histories).

Despite children being known to services the majority did not receive specialist intervention for their difficulties until they reached crisis point.

Not all professionals (examples from all professional groups) spent enough time getting to know children or had the confidence or skills to assess when children in the family had difficulties of their own. Some avoided talking to children because of this.

Parents and professionals worried about the excessive amount of caring that some children undertook, but it was difficult to see how families would survive without the help they gave. .

ORIGINAL CONTRIBUTIONS TO KNOWLEDGE AND IMPLICATIONS FOR PRACTICE

Conceptual original contribution

This study has put the concept of success at the core of working with parental mental health and child welfare. It has demonstrated that success not only happens, but is recognised by parents and children as a source for further positive change. It enables a move form a one dimensional perspective of parents as deficits carriers, to include dimensions such as their strengths, their ability to be change agents for themselves and their children, and to recognise the need for a more holistic conceptual framework to this area. It links well with the conceptual frameworks of the new meaning of recovery and of mental health promotion.

Methodological original contribution

This study makes an original methodological contribution by being the first study to focus on multiple perspectives of success with this specific population, using mixed methods, and demonstrating the usefulness of sharing the findings for the participants and the researcher.

Potential contributions to practice

The centrality of an established, consistent trusting relationship between a professional and their client (parent, child, family) featured in all of the elements of success in this study and is consistent with the literature about service user satisfaction and effectiveness (Cleaver et al. 2008, Lambert et al, 2001). This study has highlighted the contribution that parents and children make to enable these relationships to work so well.

Connecting with the people around you

When other aspects of parent's lives improved (e.g. joining a walking group; making new friends; attending a peer support group) parents were more available to their children and had more energy and emotional capacity to listen to their problems and try to help them.

Psycho-social casework and talking therapies helped to ease problematic relationships between parents and children, largely by increasing their understanding about mental health and child development, resulting in improvements in their communication with each other. Improved communication then led to a range of further positive outcomes including: *catching up* on speech and language delay; improvements in adult and child mental health; improvements in children's behaviour and feeling happier).

Keep Learning and Giving

Being supported to reach one learning goal (academic or other) emerges as a motivator to go on to achieve further success for both parents and children.

Some children who juggled high levels of caring responsibilities with school work repeatedly did well academically, regardless of what was happening at home. It was clear that school provided respite and a distraction from home for these children.

Parents and children were very interested and enthusiastic about 'giving something back' to the agencies that supported them and to other families. Participating in this

way led to reduced isolation, improved confidence and self esteem and encouraged self-efficacy and the pursuance of further opportunities for success.

Inclusion

Learning mentors and teachers supported children and helped to bridge the gap between school and home by reaching out to parents and supporting their involvement in their child's education.

Children whose difficulties remained hidden for long periods and had become entrenched were more difficult to motivate and support, indicating the important role that schools and other primary care services can play in detecting and referring on children in need of support.

Skilled and knowledgeable professionals who were able to accurately identify and match support to the needs and wishes of family members employed a range of skills and tactics to help families access support previously beyond their reach.

Help to understand mental illness was associated with high levels of service user satisfaction and empowered parents and children to participate more fully in decisions about their care. The more parents and children participated the greater the incidence of success and satisfaction.

The use of an independent budget to pay for a personal assistant for one mother resulted in very positive outcomes for the whole family.

Successful engagement via assertive outreach identified safeguarding issues that previous workers and agencies had missed because they had withdrawn when initial attempts to engage the family had failed.

Multi-agency senior manager sign-up, a commitment to co-production and a top-down bottom-up approach to service improvement for this specific population in Liverpool, has enabled changes to be made to areas of practice traditionally assigned to the 'too hard to change' box. The momentum for change is fuelled by their successes. Their work has achieved national recognition and this has helped

them attract additional funding to pursue their improvement agenda, including keeping services like Barnardos Action with Young Carers Project going.

PERSONAL REFLECTIONS ABOUT THIS STUDY

I have been interested and intimately connected with practice, research and development about parental mental health and child welfare for many years. The knowledge, experiences and different perspectives I have been able to acquire along the way have definitely helped me to carry out this study. But at other times they have definitely got in the way. Part of my full time post as a senior practice development manager at SCIE has involved project managing research and development projects about the same subject, at the same time as undertaking this research. There have been times that being so immersed in the subject both at home (research) and at work has made it difficult to separate the two. However, having a foot in both camps, so to speak, will, I hope, offer additional avenues for disseminating the research findings to a wider range of audiences.

It has been hard work and exhausting at times not least because I have other work and family responsibilities to take care of, but also because thinking long and hard about the parents, children, and professionals that participated and their circumstances, has surfaced strong emotions. I was extremely impressed and humbled in particular by parents and children's (but also professionals) willingness to take part in the research in the hope that sharing their experiences about *what works* would help professionals and ultimately other families like theirs. And it is this generosity and willingness to participate and help others in the face of great adversity, that I will remember most from undertaking this research.

THE LIMITATIONS OF THE STUDY

Sampling

1.Sample size

The sample is too small to enable generalisation. It is also skewed by having more participants from Liverpool, despite the efforts to widen the sample pool. All but two of the children/young people taking part were young carers, who are not representative of other sub-groups of children in families. However, for an

exploratory study such as this one, it is more important to understand and portray the views of the different groups of participants (Ramon et al, 2007). The problems experienced with recruitment in Lewisham seriously affected the timescale of the research and the choice of a second site had to be made swiftly and centred on choosing a site that was accessible (to myself) and that shared similar demographics to Lewisham.

2.Not all case study family members were recruited to take part in the research and the professionals involved were limited to the agencies recruited to the study. Some children in families were not invited to take part because they were too young, were not living at home; or experienced difficulties that being interviewed might exacerbate. In some families more than one child was receiving services and in two of the families I was able to interview two children from each. There were no fathers referred to the study largely because there were far fewer fathers engaged with the agencies taking part in the research.

3.There were a number of other family members in the case study families whose perspectives might have enhanced the case studies further including:

- fathers who were still supporting and caring for their children but living separately
- adult partners living at home and sharing the care of the children
- other children in the family that had not been referred to services
- grandparents who helped to look after their grandchildren and were closely supporting their child (parent)
- teachers and learning mentors whose involvement was particularly significant for some children
- CAMHS staff who had supported a number of young people who had experienced emotional and behavioural difficulties

However, this information is only known after the study has taken place and is dependent on the circumstances of each family, rather than there being a particular *missing group* that is relevant to all families. It was possible in response to the above to include CAMHS representation on the professional focus group.

FUTURE RESEARCH

The findings of this exploratory study could be used as the basis for a longitudinal study that would follow the pathway to success of a greater number of families in order to gather sufficient data, with a large enough sample to demonstrate the effectiveness of researching success for this specific population. This would strengthen the evidence base, and may impact on professionals and policy makers to consider success as core element in the work with this group.

Other family members who lived at home or who were in close contact and had shared histories with families, were not adequately included in any of the processes for assessing need (including their own needs) or supporting families. Fathers, adult partners, grandparents and others made important contributions to parents and children's lives. This then is incongruent with the arms length approach adopted by professionals to including their perspectives in assessment and care planning processes. This suggests the need for further research to explore the perspectives of other family members to further our understanding of success and to gain insights about how their perspectives can be harnessed by professionals.

Education, schools, school processes and staff actions featured highly in the findings about success and barriers to success. There were some very strong examples in the research about how when schools intervene and support children and their parents successfully this can lead to positive and far-reaching outcomes. Learning more about these successes, what helps to facilitate them and their applicability to other school settings could be an important contribution to knowledge and practice in schools and ultimately lead to earlier identification and support for children.

The fourth and final area proposed is an evaluation of the benefits associated with the parent – child relationship and the child of personalised care services (including the use of Direct Payments) for adults who are parents and have mental health problems and their children. .

CONCLUSION

This is the first study to focus on multiple perspectives of success with this specific population and by putting the concept of success at the core of working with parental mental health and child welfare it has demonstrated that success not only happens, but is recognised by parents and children as a source of further positive change.

The findings highlight that achieving one success can provide the stimulus to want to go on and achieve more. I hope that this study is the beginning of a long and evolving journey about learning from success, for me and hopefully for others. The next step of the journey I think has to be about getting more people talking about success. I plan to do this by giving careful consideration to how to get the research messages disseminated in ways that help people to understand what focusing on success is all about. One example might be in relation to the principles of practice that were found to be implicit in the work of those professionals that parents and children's valued so highly, and that were associated with positive outcomes for families. There is a potential, with some further development, to present each principle as a guideline for action in practice situations. Many of the principles are not new and will be seen by many practitioners as a statement of what good practice has always been about. They can also be seen to be similar to principles put forward by other like minded authors (Rosenfeld et al, 1993). Or they can be seen more as a preliminary map of a territory which can be further explored, and refined, and it is this last example that I have most in mind.

So whilst there is enormous relief in many ways about getting to the end of this study it seems the impetus for change is not going to stop there, nor should it.

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APPENDICES

Appendix 1: Working definition of success and key empirical indicators

Success in parental mental health and child welfare is about adequate responses to crises, coupled with the promotion of protective factors to optimise the dual outcomes of securing safeguards in the present and promoting the wellbeing and needs of all family members for the future.

An adequate response is one that:

1. Respects people's wishes and needs as individuals, including their roles and responsibilities as a parent and child in the family.
2. Is built upon a thorough understanding of the developmental needs of children; the capacities of parents or caregivers to respond appropriately to these needs and the impact of wider family and environmental factors on parenting capacity and children including the impact on parental mental illness.
3. Incorporates a public health perspective arising from the potential impact of mental health on parenting, on the child, over time and across generations.
4. Is delivered by staff who are clear about, and act upon, their responsibilities to safeguard and promote the welfare of children in need (Children Act 1989), including the contribution of these objectives to strengthen and supplement parental capacities so that children may grow up in their families, wherever possible.
5. Supports the empowerment of people using services through free sharing of professional information and knowledge.

To achieve this, the response will have to:

1. Draw upon an established knowledge base which integrates research and practitioner and user expertise.
2. Include service users and their carers in the planning and delivery of their care.
3. Attend to the needs of the parent, the child, the parent-child relationship and other significant family relationships.
4. Consider family interaction in the context of the wider family and community
5. Respect the right of the child to maintain personal relations and direct contact with both parents on a regular basis, where a child is separated from one or both parents, except if it is contrary to the child's best interests.
6. Provide continued assessment of the impact of parental mental health and separation for children and parents who are separated from each other for longer periods or permanently.
7. Incorporate a strengths and resilience-led perspective believing that change can be possible – even in unpromising conditions – and that it may start in simple ways
8. Be able to work with complexity and navigate across different service interfaces for the benefit of parents and children.
9. Promote holistic assessment with a genuine focus on prevention and promoting the health and wellbeing of all family members.
10. Include risk assessment and risk analysis that investigates opportunities and obstacles for present and future

11. Consider the timing and timeliness of interventions when prioritising services e.g. key development stages in the child's lives or timing duration and severity of illness etc.
12. Start as early as possible in crisis and does not stop with resolution of crisis.
13. Address biological, psychological and social factors.
14. Strive to make services accessible, acceptable, effective and accountable to parents with mental health problems and their children.

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Appendix 2 – Sources of data for the first phase of data collection - (research participants and files reviewed for each case study)

Case Study 1 – Lewisham			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M1	50 years	Black Caribbean
Child	C1	9 years	Black Caribbean
Child	Not interviewed	1 year 7 months	Black Caribbean
Child	Not interviewed	15 years	Black Caribbean
Partner	Not interviewed	32 years	Black Caribbean
CMHT Community Psychiatric Nurse	CMHT1		
CMHT Case File	CMHTF1		
CSC social worker	N/a case closed		
CSC File	CSCF1		
Building Bridges Social Worker	BBPrac1		
Building Bridges File	Not reviewed - social worker declined access		

Case Study 2 – Lewisham			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M2	50 years	Black Caribbean
Child	Not interviewed	21 years	Black Caribbean
Child	Not interviewed	23 years	Black Caribbean
CMHT	CMHT2		
CMHT File	CMHTF2		

Case Study 3 – Lewisham			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M3	41 years	White and Black African
Child	Not interviewed	6 years	
Child	Not interviewed	4 years	
CMHT CPN	CMHT3		
CMHT Manager	CMHTMan3		
CMHT File	CMHTF3		
CSC Social Worker	N/A/Case closed		
CSC File	CSCF3		

Case Study 4 – Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M4	50 years	White British
Child	C4	18 years	White British
Child	Not interviewed	20 years	
Child	Not interviewed	22 years	
Child	Not interviewed	24 years	
CMHT	Not interviewed		
CMHT Case File	??		
Barnardos Social Worker	Bar4		
Barnardos Supervisor	BarMan4		
Barnardos File	BarF4		

Case Study 5 - Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M5	52 years	White British
Child	C5	15 years	White British
CMHT	Not interviewed		
CMHT Case File	CMHTF5		
Barnardos Social Worker	Bar5		
Barnardos supervisor	BarMan5		
Barnardos File	BarF5		

Case Study 6 – Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M6	51 years	White British
Child	C6	14 years	White British
Child	Not interviewed	25 years	White British
Child	Not interviewed	30 years	White British
CMHT	Not interviewed		
CMHT File	CMHTF6		
Barnardos Social Worker	Bar6		
Barnardos Supervisor	BarMan6		
Barnardos File	BarF6		

Case Study 7 – Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**

Mother	M7	36 years	White British
Child	C7	9 years	White British
Child	Not interviewed	6 years	White British
Child	Not interviewed	4 years	White British
CMHT CPN/Man	CMHTMan7		
CMHT File	CMHTF7		
Barnardos Social Worker	Bar7		
Barnardos Supervisor	BarMan7		
Barnardos File	BarF7		

Case Study 8 – Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M8	48 years	Black British
Child	C8	11 years	Black British
Child	Not interviewed	15 years	Black British
CMHT	Not interviewed		
CMHT File	CMHTF8		
Barnardos Social Worker	Bar8		
Barnardos Supervisor	BarMan8		
Barnardos File	BarF8		

Case Study 9 - Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M9	50 years	White British
Child	C9a	16 years	White British
Child	C9b	24 years	White British
Child	Not interviewed	24 years	White British
Child	Not interviewed	18 years	White British
CMHT	Not interviewed		
CMHT File	CMHTF9		
Barnardos Supervisor and Case Worker	BarMan9		
Barnardos File	BarF9		

Case Study 10 - Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M1	45 years	White British
Son	C10a	13 years	White British

Daughter	C10b	15 years	White British
CMHT	Not interviewed		
CMHT File	CMHTF10		
Barnardos Social Worker	Bar10		
Barnardos Supervisor	BarMan10		
Barnardos File	BarF10		

Case Study 11 - Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M11	44 years	Black African
Child	C11	15 years	Black African
Child	Not interviewed	8 years	Black African
Child	Not interviewed	9 years	Black African
CMHT	CMHT11		
CMHT File	CMHTF11		
Barnardos Social Worker	Bar11		
Barnardos Supervisor	BarMan11		
Barnardos File	BarF11		

Case Study 12 - Liverpool			
Participant	**Coding**	**Age**	**Ethnicity**
Mother	M12	36 years	White British
Child	C12	12 years	White British
CMHT	Not interviewed		
CMHT File	CMHTF12		
Barnardos social worker	Bar12		
Barnardos Supervisor	BarMan12		
Barnardos Case File	BarF12		

Appendix 3 – Participant Information Sheets

'What works' – Researching success in parental mental health and child welfare work'

PARTICIPANT INFORMATION SHEET

- Parents -

Dear

Invitation to take part

My name is Marie Diggins and I am a research student at Anglia Ruskin University doing a PhD degree. I am also a social worker and I have worked with children and adults with mental health problems for many years.

As part of my studies I will be doing some research in Lewisham and I would like to invite you to take part. Before you decide whether to take part in it or not, it is important for you to understand why the study is being carried out and what it will involve for you.

To help you decide this information sheet spells out the purpose of this study and your part in it. Please take time to read this information and talk about it with your family, friends or others if you wish.

The worker who gave you this information sheet knows about the study too and you may find it helpful to speak to them or ask them any questions you might have. You can also ask me questions if you want to and my contact details can be found on page 3 of this information sheet.

Why are we doing this research?

This study is interested in finding out about situations that turn out well for parents with mental health problems and their children.

Parents and children who need support may find it is only there for them in times of crises. The support may not take notice of the needs and wishes of the whole family. Sometimes a lot of help and support is given but nothing much seems to change for the better for the parent, the child or the whole family.

However, we know that there are some families who experience a lot of difficulties and where the future looks uncertain who are supported successfully. It is these families the study wants to know more about.

Finding out more about what makes it possible for families to experience positive and lasting changes will be very useful information to share with others who are trying to achieve similar results.

How will the information needed for the study be found?
Individual meetings will be arranged so that I can talk to parents and children from 12 different families and, if the families give permission I will also arrange to meet with the Community Mental Health Team and Children and Family workers that are already working with them. Everyone will be interviewed separately.

I will also want to read some of the notes in files that the Community Mental Health Team and the Children and Family Team keep about the same families if family members give permission for this to happen.

After all this has been done I will carry out three separate group interviews with parents, children and staff to discuss some of things that I have found out in the first part of the study. Family and staff who took part in the individual interviews will NOT be allowed to take part in the group interviews.

***PLEASE NOTE**: At no time will members of the same family or the staff they work with be interviewed together.*

All of the information gathered will then be written up in one final report.

Why have I been asked to take part?
As a parent your views are important to this study. By hearing what you have to say I hope to learn more about what support works from a parent's point of view and what you think needs to happen to make sure things turn out well.

If you give your permission and your child is happy to talk to me I would like to get their point of view too. They would meet with me separately and they can have someone they know in the meeting with them if they wish. There is a separate information sheet for children and young people explaining what taking part would mean for them and a copy of this will be given to you.

What if I don't want to talk to you?
You don't have to talk to me if you don't want to. If you do you will be given a copy of this information sheet to keep and you will be asked to sign a consent form to say you are willing to take part.

You will also be given a separate children and young people's information sheet and a parental consent form which you will need to sign if you agree to your child taking part in the study.

You will be able to change your mind at any time after this without giving a reason and if you don't want to answer a particular question when we meet, then you don't have to. If you decide not to take part at anytime this will not affect the care you or any other member of your family receives.

What will happen to me if I take part?
You will be invited by the person that gave you this information sheet to come along to take part in one interview with me at their office. The interview will take no more than an hour. When we meet I will ask you to think of some examples of times when things have turned out OK or better than you hoped, for you and your family and why you think they happened in this way.

If you want you can have someone you know with you when we talk – this is up to you. You might want to ask the person who gave you this form. You will be able to take a break during the interview if you want to.

With your permission I would like to tape-record our conversation, but you can ask me to switch the tape-recorder off at any time.

After we have talked I will listen to the tape and put down on paper what you have said and I will send this to you to check. If you want to change anything you said you will have the chance to do so.

Expenses and payments:
If you need to take a bus or train to come to talk to me and get back home again I can pay for your tickets and as a thank you for helping me with my research I would like to give you a £15.00 gift voucher of your choice.

What are the possible disadvantages and risks of taking part?
Sometimes discussing things can make you think about difficult times. If this does happen to you I will make sure that I will be available after we finish talking and you can also phone me for the next two weeks. I will also make sure that the person who gave you this information is also available for you.

What are the possible benefits of taking part?
There are no intended benefits.

What if there is a problem?
If you have a concern about anything to do with the study, you should ask to speak to me or the worker who gave you this information sheet and we will do our best to help you.

My contact details are:
Marie Diggins
SCIE
1st Floor Goldings House
2 Hay's Lane
London
SE1 2HB
Tel no 020 7089 6840
Email: marie.diggins@scie.org.uk

If you are still unhappy and wish to complain, you can do this and by contacting me and I will put you in touch with someone at the University who will be able to deal with your complaint.

Will what I tell you be kept private?
What you say is between you and me and my research supervisors. What you say is therefore private.

The only information that would not be private would be if you were to tell me anything that would lead me to think you or someone else is in immediate danger of serious harm then I would have to pass this information on to someone who might be able to help. If this should happen then I would talk to you about this first and explain what might happen.

You can have a copy of the tape of our talk if you wish, and you can ask to see all the information I have about you at any time.

I will store any notes and the tapes of our conversations in a locked cabinet where I work and any computer files I have will be protected with a password only I will know. I will store this information for up to 18 months until the study is finished and everything has been written up in a final report, then all of the notes and tapes will be destroyed.

When I write up the final report it will not be possible to identify you from things you have said.

Who is organising and funding the research?
I (Marie Diggins) am the researcher for this study and I am being sponsored to do this work as part of my PhD degree studies by Anglia Ruskin University. There is no funding for this research and I (the researcher) am not receiving any payment for carrying it out.

Who has reviewed the study?
All research in the NHS and Local Authority is looked at by an independent group of people, or in some cases more than one group to protect your safety, rights, wellbeing and dignity. This study has been reviewed and passed by the South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee, Lewisham Research Governance Board and Anglia Ruskin University.

What will happen to the results of the research study?
When the project is over, I will write to you to tell you what I have found out. I will also invite you and the other people who have taken part to an event in Lewisham where I will be talking about the results of the study. I will let you know the date when I write to you.

Thank you for thinking about taking part and taking time to read this
Please ask any questions if you need to

Marie Diggins
Researcher

What works – Researching success in parental mental health and child welfare work

PARTICIPANT INFORMATION SHEET

- Children –

Dear

Invitation to take part

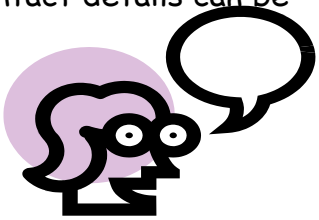
My name is Marie Diggins and I am a research student at Anglia Ruskin University doing a PhD degree. I am also a social worker and I have worked with children and adults with mental health problems for many years.

As part of my studies I will be doing some research in Lewisham and I would like to invite you to take part.

Before you decide whether to take part in it or not, it is important for you to understand why the study is being carried out and what it will involve for you.

To help you decide this information sheet spells out the purpose of this study and your part in it. Please take time to read this information and talk about it with your family, friends or others if you wish.

The worker who gave you this information sheet knows about the study too and you may find it helpful to speak to them or ask them any questions you might have. You can also ask me questions if you want to and my contact details can be found on page 4 of this information sheet.



Take time to decide whether you wish to take part.

Why are we doing this research?

This study is interested in finding out about situations that turn out well for parents with mental health problems and their children.

Parents and children who need support may find it is only there for them in times of crises. The support may not take notice of the needs and wishes of the whole family. Sometimes a lot of help and support is given but nothing much seems to change for the better for the parent, the child or the whole family.

However, we know that there are some families who experience a lot of difficulties and where the future looks uncertain who are supported successfully. It is these families the study wants to know more about to share with others.

Finding out more about what makes it possible for families to experience positive and lasting changes will be very useful information to share with others who are trying to achieve similar results.

How will the information needed for the study be found?
Individual meetings will be arranged so that I can talk to parents and children from 12 different families and, if the families give permission I will also arrange to meet with the Community Mental Health Team and Children and Family workers that are already working with them. Everyone will be interviewed separately.

I will also want to read some of the notes in files that the Community Mental Health Team and the Children and Family Team keep about the same families if family members give permission for this to happen.

After all this has been done I will carry out three separate group interviews with parents, children and staff to discuss some of things that I have found out in the first part of the study. Family and staff who took part in the individual interviews will NOT be allowed to take part in the group interviews.

NOTE: **At no time will members of the same family or the staff they work with be interviewed together**.

All of the information gathered will then be written up in one final report.

Why have I been asked to take part?
As a child or young person with a parent with a mental health problem your views are very important to this study. By hearing what you have to say I hope to learn more about what works from a child or young person's point of view and what you think needs to happen to make sure things turn out well.

What if I don't want to talk to you?
You don't have to talk to me if you don't want to. If you do you will be given a copy of this information sheet to keep and you will be asked to sign a consent form to say you are willing to take part.

You will be able to change your mind at any time after this without giving a reason and if you don't want to answer a particular question when we meet, then you don't have to. If you decide not to take part at anytime this will not affect the care you or any other member of your family receives.

What will happen to me if I take part?
You will be invited by the person that gave you this information sheet to come along to take part in one interview with me at their office. The interview will take no more than an hour. When we meet I will ask you to think of some examples of times when things have turned out OK or better than you hoped, for you and your family and why you think they happened in this way.

If you want you can have someone you know with you when we talk – this is up to you. You might want to ask the person who gave you this form. You will be able to take a break during the interview if you want to.

With your permission I would like to tape-record our conversation, but you can ask me to switch the tape-recorder off at any time.

After we have talked I will listen to the tape and write down what you have said and I will give this to you to check. If you want to change anything you said you will have the chance to do so.

Expenses and payments:
If you need to take a bus or train to come to talk to me and get back home again I can pay for your tickets and as a thank you for helping me with my research I would like to give you a £10.00 gift voucher.

What are the possible disadvantages and risks of taking part?
Sometimes discussing things can make you think about unhappy times. If this does happen to you I will make sure that I will be available after we finish talking and you can also phone me for the next two weeks. I will also make sure that someone who you know very well is also available for you.

What are the possible benefits of taking part?
There are no intended benefits.

What if there is a problem?

If you have a concern about anything to do with the study, you should ask to speak to me or the worker who gave you this information sheet and we will do our best to help you.

My contact details are:
Marie Diggins
SCIE
1st Floor Goldings House
2 Hay's Lane
London
SE1 2HB
Tel no 020 7089 6840
Email: marie.diggins@scie.org.uk

If you are still unhappy and wish to complain, you can do this by contacting me and I will put you in touch with someone at the University who will be able to deal with your complaint.

Will what I tell you be kept private?
What you say is between you and me and my research supervisors. What you say is therefore private.

The only information that would not be private would be if you were to tell me anything that would lead me to think you or someone else is in immediate danger of serious harm then I would have to pass this information on to someone who might be able to help. If this should happen then I would talk to you about this first and explain what might happen.

You can have a copy of the tape of our talk if you wish, and you can ask to see all the information I have about you at any time.

I will store any notes and the tapes of our conversations in a locked cabinet where I work and any computer files I have will be protected with a password only I will know. I will store this information for up to 18 months until the study is finished and everything has been written up in a final report, then all of the notes and tapes will be destroyed.

When I write up the final report it will not be possible to identify you from things you have said.

Who is organising and funding the research?
I (Marie Diggins) am the researcher for this study and I am being sponsored to do this work as part of my PhD degree studies by Anglia Ruskin University. There is no funding for this research and I (the researcher) am not receiving any payment for carrying it out.

Who has reviewed the study?
Before any research goes ahead it has to be checked by one or more Research Ethics Committees depending on the type of research. They make sure the research is fair. This study has been checked by the South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee, Lewisham Research Governance Board and Anglia Ruskin University.

What will happen to the results of the research study?
When the project is over, I will write to you to tell you what I have found out. I will also invite you and the other people who have taken part to an event in Lewisham where I will be talking about the results of the study. I will let you know the date when I write to you.

Thank you for thinking about taking part and taking time to read this
Please ask any questions if you need to

Marie Diggins
Researcher

‘What works’ – Researching success in parental mental health and child welfare work’

PARTICIPANT INFORMATION SHEET
- Staff -

Dear

Invitation to take part
My name is Marie Diggins and I am a research student at Anglia Ruskin University doing a PhD degree. I am also a social worker and I have worked with children and adults with mental health problems for many years.

As part of my studies I will be doing some research in Lewisham and I would like to invite you to take part.

To help you decide whether to participate in the research or not, it is important for you to understand why the study is being carried out and what it will involve for you. To help you decide this information sheet spells out the purpose of this study and your part in it. Please take time to read the following information carefully. Talk to others about the study if you wish.

You can also ask me questions if you want and my contact details can be found on page 3.

What is the purpose of the study?
This study is interested in finding out more about situations which turn out well for parents with mental health problems and their children.

Some parents and children who need support find it is only available in times of crisis and may not take into consideration the needs and wishes of the whole family. Sometimes a lot of help and support is given but nothing much seems to change for the better for the parent, the child or family as a whole.

However, we know that there are some families who are faced with a lot of difficulties and where the future looks uncertain who are supported successfully. It is these families we want to know more about to share with others. Finding out more about what makes it possible for families to experience positive and lasting changes will be useful information to share with others.

How will you find out what you need to know?
I will gather the information I need by carrying out individual interviews with 12 families (a parent and a child from each) and the supervisor and key worker from the following agencies: Community Mental Health Team, Children and Family team,

Family Health ISIS and Lewisham Building Bridges who are in contact with the same families.

I also plan to read the assessment, care plan and review documents from the Community Mental Health Team and Children and Family Team files for the same families, if family members give permission for this to happen.

After all the interviews have taken place and the file information has been read a small number of group interviews with parents, children and staff will be held to discuss any themes or issues arising from the interviews and file reviews. Families and staff participating in the first stage of the research i.e. individual interviews will not be asked to join the group interviews.

NOTE: *At no time will members of the same family or the professionals they work with be interviewed together.*

All of this information will then be analysed and written up in a final report.

Why have I been invited to take part?
As a professional involved in providing support to parents with mental health problems and their children your views are central to this study. By obtaining your views and the views of other professionals we hope to learn more about 'success' means from a professional perspective and what you believe are the main things that need to be in place to achieve success.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part I will ask you to sign a consent form to show you have agreed to take part.

You are free to withdraw at any time, without giving a reason. A decision not to take part or withdrawal from the study at any time will not affect your rights as a member of staff.

What will happen to me if I take part?
I would like to meet with you at your office for approximately one hour. During this time I will ask you some questions about the person you have been working with and their family (they will have already been identified to take part in the study). I will ask you to think about examples of things that have worked out well or better than previously expected for the family and why you think things have happened in this way.

Before the start of your interview I will ask for your consent for the interview to be audio-taped. This taped discussion will then be written up and a copy will be sent to you to check the content for accuracy.

You will be able to take a break during the interview if you wish.

In a small number of situations I may want to organise a short follow up conversation by phone to clarify any points or address any gaps in the information once the interview is written up.

Expenses and payments:
This study is not funded; I am therefore only able to pay travelling expenses to and from the interview and offer a small token of thanks in the form of a gift voucher for taking part to the **parents** and **children** taking part only.

What are the possible disadvantages and risks of taking part?
It is possible that the discussion may make you relive some unhappy personal or professional experiences of your own. In this eventuality I will be available at the end of the interview and by phone for the following two weeks.

What are the possible benefits of taking part?
There are no intended benefits for individual participants.

What if there is a problem?
If you have a concern about anything to do with the study, you should contact me in the first instance and I will do my best to help you.

My contact details are:
Marie Diggins
SCIE
1st Floor Goldings House
2 Hay's Lane
London
SE1 2HB
Tel no 020 7089 6840
Email: marie.diggins@scie.org.uk

If you remain concerned and wish to complain formally, I will put you in contact with the relevant person at the University.

Will my taking part in the study be kept confidential?
Yes. The data will be anonymised and the audio file and notes from the interview will be kept in a locked filing cabinet at my office address. The data will be stored for no longer than 18 months, after which the data will be destroyed. During this time the data will be accessed for writing up and analysis only by myself.

The only information that would not be private would be if you were to tell me anything that would lead me to think you or someone else is in immediate danger of serious harm then I would have to pass this information on to someone who might be able to help. If this should happen then I would talk to you about this first and what might happen.

The handling processing, storage and destruction of your data are compliant with the Data Protection Act 1998.

Who is organising and funding the research?

I (Marie Diggins) am the researcher and I am sponsored by Anglia Ruskin University to organise and carry out this study in Lewisham. There is no funding for this research and I will not be receiving any payment for carrying out the work.

Who has reviewed the study?
All research in the NHS and Local Authority is looked at by an independent group of people, or in some cases more than one group to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee, Lewisham Research Governance Board and Anglia Ruskin University.

What will happen to the results of the research study?
I will send out the findings in a research report, which you and the other people involved in the study will also receive. None of the participants, including you, will be identified in the report, or in any other publications about the research.

I will also present the findings in other ways including at a local event in Lewisham and you along with the other research participants will be invited to come along to that once a date has been set nearer to the end of the research process.

Thank you for considering taking part and taking time to read this sheet
Please ask any questions if you need to

Marie Diggins
Researcher

Appendix 4 – Consent forms

‘What works’: Researching success in parental mental health and child welfare work’
Consent form for children

Dear
Thank you for agreeing to take part in this research. This letter is for you to keep to remind you that you have agreed to take part in this research project, however, you can change your mind at any time and your name will not be used in any reports written about the research.
Yours sincerely,

Marie Diggins – Researcher/Anglia Ruskin University

CONSENT FORM:
I agree to talk to Marie Diggins (who is the researcher for this study). I understand that Marie will be recording our conversation on a tape recorder. Marie will listen to the tape to help remember our conversation and exactly what I have said.

Some of the things I say may be included in the research report and the report may be used to write articles or give presentations at conferences. My name will not be used. Nothing I say will be written in a way that people will be able to work out that it was me that said it.

I understand that in the unlikely event that I say anything that leads Marie to think that I or anyone else is in immediate danger of serious harm that Marie will have to pass the information on to someone who might be able to help. If this happens Marie will talk to me about what she will need to do and what might happen.

Please answer the following questions by placing a tick or a cross in the box

1. I have read the information sheet telling me about the research and had the opportunity to ask questions ☐
2. I would like to take part in the project ☐
3. Later on I know I can leave the project if I change my mind ☐
4. I am happy for the talk to be tape-recorded ☐

Name: ……..

Sign here: ……..Date:……..

Researcher…….

Sign here:……..Date…….

One copy for the participant and one copy for the researcher.

‘What works’: Researching success in parental mental health and child welfare work’
Confidentiality and consent form for parent/guardian

Dear (Parent/Guardian’s name),
Thank you for agreeing to take part in this research. This letter is for you to keep for future reference regarding confidentiality and consent.

Yours sincerely,

Marie Diggins – Researcher/Anglia Ruskin University

CONSENT FORM:
I agree to talk to Marie Diggins (who is the researcher for this study). I understand that Marie will be recording our conversation on a tape recorder. Marie will listen to the tape to help remember our conversation and exactly what I have said.

Some of the things I say may be included in the research report and the report may be used to write articles or presentations for conferences. My name will not be used and quotes will be anonymous.

I understand that in the unlikely event that I say anything that leads Marie to think that I or anyone else is in immediate danger of serious harm that Marie will have to pass the information on to someone who might be able to help. If this happens Marie will talk to me about what she will need to do and what might happen.

Please answer the following questions by placing a tick or a cross in the box

5. I have read the information sheet telling me about the research and had the opportunity to ask questions ☐
6. I would like to take part in the project ☐
7. Later on I know I can leave the project if I change my mind ☐
8. I am happy for the talk to be tape-recorded ☐

Name: ……..

Sign here: ……..Date:……..

Researcher…….

Sign here:……...Date…….

One copy for the participant and one copy for the researcher.

‘What works’: Researching success in parental mental health and child welfare work’

Parental confidentiality and consent form for children

Dear

Thank you for agreeing that your child can take part in this research. This letter is for you to keep for future reference regarding confidentiality and consent.

Yours sincerely,

Marie Diggins – Researcher/Anglia Ruskin University

CONSENT FORM:

I give consent for my child to talk to Marie Diggins (who is the researcher for this study). I understand that Marie will be recording the conversation on a tape recorder. Marie will listen to the tape to help remember the conversation and exactly what was said.

Some of the things my child says may be included in the research report and the report may be used to write articles or presentations for conferences. My child’s name will not be used and quotes will be anonymous.

I understand that in the unlikely event that my child says anything that leads Marie to think that he/she or anyone else is in immediate danger of serious harm that Marie will have to pass the information on to someone who might be able to help. If this happens Marie will talk to me about what she will need to do and what might happen.

Please answer the following questions by placing a tick or a cross in the box

1. I have read the information sheet telling me about the research project and had the opportunity to ask questions ☐
2. I agree to my child taking part in the research project ☐
3. I know I can withdraw my consent later on if I change my mind ☐
4. I am happy for the talk to be tape-recorded ☐

I am the parent/legal guardian of…….

Name: ……..

Sign here: ……..Date:……..

Researcher…….

Sign here:……..Date…….

One copy for the participant and one copy for the researcher.

A study about what works': Researching success in parental mental health and child welfare work'

Confidentiality and consent form for staff

Dear
Thank you for agreeing to take part in this research. This letter is for you to keep for future reference regarding confidentiality and consent.

Please answer the following questions by placing a tick or a cross in the box

1. I have read the information sheet telling me about the research and had the opportunity to ask questions ☐
2. I agree to take part in this research project ☐
3. My name or any other identifiable characteristics will not be used and quotes will be anonymous ☐
4. I am happy for the interview to be tape-recorded ☐

Name: .....

Sign here: ……..Date:……..

Researcher: Marie Diggins

Sign here:……...Date…….

Yours sincerely,

Marie Diggins – Researcher/Anglia Ruskin University

One copy for the participant and one copy for the researcher.

Appendix 5 - Questions for individual interviews

INTERVIEW QUESTIONS - CHILDREN AND YOUNG PEOPLE
Child's details – Case Study Number (*to be inserted)*
Name:
Date of birth:
Health and social care agencies in contact with:
Receipt of signed consent form parent: **YES/NO**
Receipt of signed consent form child/young person: **YES/NO**
Request to see transcript of interview: **YES/NO**
Introductory question **Q1. Let's start by getting a bit of a picture about you and your family?**
Prompts: • So who lives at home with you? What are their names and how old are they? • What are your favourite things at school/ college/work? • What don't you like? • What do you like doing when you are not at school? • Are there some things that you do as a whole family that you enjoy?
Q2. Do you know when your (*Mum or Dad)* first started to get some help for their mental health problems?
Prompts: • Who did they see? • Can you tell me about tell me about what was happening to your Mum or Dad and how they were feeling and behaving then? • When did you first notice there was a problem? • What did you think was happening? • How did these difficulties effect how you and your ***(Mum or Dad)*** got on? • How did the difficulties effect how your ***(Mum or Dad)*** got on with other family members and with other people? • Do any of the people that help your ***(Mum or Dad)*** see you as well? • What do they see you about?
Q3. What about you? Do you see anyone or go somewhere to get some support for yourself?
Prompts: • Did you get in touch with them or did they get in touch with you? • What is the name of the person you see? • How long have you been seeing them/receiving this support? • What help or support do they offer you? Is there anyone that you can talk to about: • Any worries you had about your Mum or Dad? Or, • Any worries about yourself? Or, • Any worries about other family members (siblings etc.)

Q4. Can you think of a few examples of things that have worked out well or are better than they used to be since you and your family have been getting the support that you have told me about?
Prompts & examples: *The examples can be things that:* • have been successful, or • worked out better than expected, or • better than previously experienced E.g.: Mum or Dad is feeling better, has not had to go into hospital, people are getting on better with each other at home, can talk about things more easily, have fun together, have someone else to talk to, school understands better.
Supplementary questions: **Q4A.** How did this work out for you?
Q4B. How did this work out for your Mum/Dad?
Q4B. How did this work out for the whole family?
Q4C. What did you do to help make sure that this worked out so well, or better than before?
Q4D. What did other people do? (e.g. family members, friends, key worker, doctor, social worker, teacher)
Q4E. Was there anything else that happened or changed that helped make things work out in this way? (e.g. new key worker, referral to another service, returning to work, receipt of a new service, move to better housing, new supportive partner, improved mental health, new friends, getting on better with Mum/Dad, better understanding of mental illness).

INTERVIEW QUESTIONS - PARENTS
PARENT'S DETAIL'S – CASE STUDY NUMBER: *(to be inserted)* **(to be confirmed at interview)**
Name:
Date of birth/age:
Contact telephone number(home or key worker):
Child's date of birth/age:
Receipt of signed consent form: **YES/NO**
Receipt of signed consent form for child: **YES/NO**
Request to see transcript of interview: **YES/NO**
Q1. Introductory question **I would like to start by asking you a few questions about yourself and your family**

Prompts:

- How long having you been living at this address?
- Who else lives at home?
- Tell me about your children, what are they like, what do they like doing?
- Are you a full time Mum/Dad or are you working at the moment?
- What did you do before?
- If you get any spare time what do you like to do and who do you like to see?
- What about other family and friends?

Q2. Can you tell me when you first came into contact with services and what led to it?

***Prompts*:**

Which service was this?

- When was it?
- Did you contact them or did they contact you?
- Do you have a key-worker, How long have they been your key-worker

What was happening that led up to the contact being made?

- What was that like for you?
- What was that like for your child?
- What was that like for the rest of your family?

What other services for you or your children?

- (e.g. universal support, health visitor, GP, CMHT, CSC, ISIS, Building Bridges, Carers, GP, Health Visitor other)

Are you still in contact with the same services? If not when did contact stop?

Q3. This research is about learning from positive changes that parents and children have experienced. It is also about finding out what happened in these situations to make then turn out in this way.

Can you think of a few examples of things have turned out well or better than expected since you and your family first had contact with the services you have told me about?

Prompts:

Examples can be situations that:

- have been successful, or
- worked out better than expected, or
- better than previously experienced

The examples don't have to be something big; it could be a small change but something that has had a positive and lasting impact, e.g. mental health improved, fewer admissions, new treatment that has less side effects, more time to spend with children, started a new job/training, new or improved relationships.

For each example:

Q3A. How did this work out for you?

Q3B. How did this work out for your child/children?

Q3C. How did this work out for the whole family?
Q3D. What did you do to help make sure that this worked out so well, or better than before?
Q3E. What did other people do? (e.g. family members, friends, key worker, doctor, social worker, teacher)
Q3F. Was there anything else that happened or changed that helped make things work out in this way? (e.g. returning to work, getting finances sorted, moving house, new partner or improved relationships in the family and with friends, better understanding of difficulties and how to avoid problems).

Interview Questions - Practitioner/Manager/Supervisor
PRACTITIONER DETAILS (CMHT, CSC, Building Bridges or Family Health ISIS) DETAILS – CASE STUDY NO: *(to be inserted)*
Name:
Professional qualifications:
Number of years qualified:
Job title:
Number of years in this post:
Organisation and team:
Telephone number:
e-mail address:
Line manager's details
Name:
Job title:
Telephone number:
e-mail:
Key-worker to (name of child/parent/family):
Receipt of signed consent form: **YES/NO**
Consent to speak to line manager about supervision for this case only **YES/NO**
Introductory question **Q1.** How much of your work involves parents who have mental health problems? And what kind of support does your agency offer?
Prompt: what does this work involve?
Case Study Family I now want to ask you some questions about XX and his/her family. **Referral** **Q2.** What was the reason for the referral to your service?
Prompts: • What had led to the referral? • Who made the referral and when? • What was the referrer requesting? • Were any other issues identified during your assessment? (housing, domestic violence, financial....etc).

Practitioner involvement

- When did you get involved?
- How have you been working with them?

Q3. – Stakeholder involvement

- Who else is involved in supporting this family?

Prompt:

- Other professionals, organisations, family members, friends
- How have they been working with or supporting them?
- What contact do you have with these services/people?

Q4. Can you think of 2 or 3 situations that have taken place in the life of the parent, child or family which demonstrate positive change?
Then once you have thought of some examples I want to ask you a few questions about each one.

Prompt:

Positive change or successful outcome

- have been successful, or
- worked out better than expected, or
- better than previously experienced

E.g. improvement in mental health, improved relationships, shorter admissions, better understanding of parental mental health and child welfare, handling conflict better than before.

Q4A. Can you describe your (first, second, third) example in more detail?

Prompt:

How do you think the different family members experienced this? What you described.

Q4B. Can you identify what led to the successful outcomes in the (first, second, third) example you have given?

Q5C. What do you think you contributed to achieving the successful outcomes you describe?

Prompt:

- re-instated benefits, facilitated speedy access to mental health care, helped family to understand the potential impacts of mental illness etc.
- line management support, supervision, multi-agency and multi-disciplinary working (for practitioner)
- providing support to the key worker, supervision and management, managing across the interface between services (for manager/supervisor)

Q4D. What helped you to carry out your work in this way?

Prompt:

- personal and professional experience and attributes
- training
- supervision
- team and organisation culture
- inter-agency protocols or practice guidance

Q4E. What did other people contribute to achieving the positive outcome you describe?

Prompt:

- Working together relationships
- Agency ethos, values, principles, protocols

- Managers
- Professionals
- Family
- Friends

Q4F. Is there anything else that you haven't mentioned already that you think was an important factor in achieving the successful outcome you describe?

Appendix 6 – Case study summaries (two examples completed)

Case study summary 4

Family composition and circumstances

M4 (50 years) lives alone at home with her youngest son C4 (18 years) who is a young carer. M4's daughter lives nearby in her own flat and drops in to see her Mum most days. Her two other sons went to prison in 2008, the eldest of whom has just been released and is in regular contact. C4's Dad died suddenly when C5 was a toddler. There is little contact with extended family. C4 is working in a local restaurant and plans to join the army next year. The home has undergone significant renovation which has been very positive for M4 and C4 as it was previously in serious disrepair.

Mother M4

Psychiatric history

M4 has a long history of drug-resistant depression, a feature of which is agoraphobia, she has not left the house in the in the last eight years. She has self harmed in the past but is not currently doing so. She has used alcohol at times, and cannabis which she says helps her to eat. When her mood deteriorates she lacks almost any motivation; her self-care deteriorates and she spends most of her time in her bedroom. Her lack of motivation and agoraphobia made it difficult in the past for her to maintain contact with mental health services. This has improved considerably in the last two years as the CMHT and psychiatrist now visit her at home.

Past history

M4 has experienced a great deal of loss in her life; as a child she was in foster care and did not re-establish contact with her Mum until she was 19. Her Mum died shortly after this and her relationship with the father of C4's two brothers broke down. She separated from her daughter's father when he returned to his birth country to serve in the army. C4's father died when he was a toddler. M4's brother, to whom she was close, died from a heart attack a few years ago.

Health and wellbeing

M4 has high blood pressure. She has a tendency to neglect herself physically when her mood is low. Previously the family lived a lot on take-aways but M4, when she is well, is cooking more and so is C4 and they are visibly benefitting from the results of this. M4 continues to miss her son who is still in prison and is upset by this.

Accommodation type/status and adequacy

The family home is a housing association property. M4 would really like to be able to get a two bedroomed flat in a different area and hopes that this would assist in her feeling less paranoid about going outside.

Employment/education/training issues

M4 has not worked since her children were small more than 20 years ago.

Finances/welfare benefits/money matters

M4 receives welfare benefits and her financial situation is difficult. She continually struggles to manage although she acknowledges that C4's wage makes a significant difference.

Social and daily living skills
The family are very close but otherwise M4 has little contact with anyone else because of her agoraphobia. She particularly values the visits and phone calls that the Barnardos social worker makes to her and the opportunity she has then to talk. How much M4 can do around the house e.g. cooking, cleaning etc. is largely dependent on her mood. C4 carries out the bulk of these tasks.

Child C4
Contact with services
C4's first contact with services was via his school. They referred him to Connexions and he was allocated a support worker who recognised he was a young carer and referred him to Barnardos Action with Young Carers. The Connexions worker and Barnardos social worked together to support both M4 and C4. Both C4 and mum have received continuous support from Barnardos and the social worker there has become an important person in both of their lives. During this time, C4 has received regular respite breaks from caring, has attended a number of training courses including leadership training, and his confidence, self esteem and relationship with his peers have improved.

Presenting problems
C4 first came to the attention of services because of poor school attendance. It soon became clear he was a young carer under a considerable amount of pressure and his mum was not in receipt of any CMHT support at the time. C4's Mum was very worried about him; he was very unhappy and he was associating with people involved in petty criminal activity and not going to school, and she could not get him to listen to her. This was making her mental health problems worse and consequently his caring tasks harder.

Caring role
C4's caring responsibilities started when he was very young and they increased considerably when his sister moved into her own flat in 2008. He continues to cook, clean, does the shopping and pays the bills. However his caring responsibilities have changed in three areas: he is less concerned that his Mum won't take medication because she is on new medication and is happy with its effect and she doesn't forget to take it; he no longer has to make sure his Mum is safe at night because she mostly sleeps upstairs in her bed, instead of in her chair in the lounge; and the biggest change, in the area which C4 believed was his main area of responsibility, supporting his mum emotionally. C4 believes his mum to be less anxious and less depressed.

Health and wellbeing
Cannabis use has been common in C4's household and those he visits, but C4 does not use cannabis. His physical and mental health are improved as he is now taking more exercise, eating more healthily, is less worried about his Mum and gets respite from caring through work and short breaks. His relationship with his social worker at Barnardos is very important to him.

Education/training and employment
C4 secured a job out of choice and without professional support and has maintained this job for over a year. He is saving up and has been committed to a driving programme funded by Barnardos - he is taking lessons.

Case study summary 5

Family composition and circumstances
M5 (50 years) has three children, her youngest daughter C5 (15 years) lives at home with her and her son (27 years) and oldest daughter (25 years) live independently. M5 has been heavily reliant on her children for emotional and practical support. Her son and eldest daughter have now taken the decision to separate themselves from her and this is particularly unsettling for M5. Her youngest daughter C5 is a young carer and M5 relies on her to assist around the home with domestic chores and some of her activities of daily living when her mood is low. M5 has in the past also relied on her eldest daughter with regard to support.

Mother 5
Psychiatric history
M5 has suffered with depression since 1998 and has been known to mental health services since 2007. Her primary mental health diagnosis is recurrent depression with episodes of paranoid delusions. She has PTSD and personality disturbance. She has a history of experiencing thoughts of self-harm with episodes of suicidal ideation. She can become uninhibited when unwell and has been found wandering down by the docks in her night clothes. Her insight into her problems is minimal although she is aware of fluctuations in her mood. She tries to be compliant with her medication but finds it difficult to tolerate medicines due to side effects and her anxiety. Whilst she is willing to engage with mental health services when she is unwell, she is likely to withdraw and isolate herself.

Past history
M5 was born and raised in Liverpool. Her parents are both deceased. M5 had a happy childhood with a good and safe up-bringing. At age 15 she was the victim of sexual abuse from a relative. M5 experienced very severe domestic violence from her children's father and that relationship ended about 13 years ago. There have been episodes of harassment from neighbours in her previous neighbourhood.

Health and wellbeing
M5 is asthmatic and has recurrent headaches. She has a history of deep vein thrombosis and pulmonary embolisms.

Accommodation type/status and adequacy
M5 recently moved into a three bedroom terraced house to be nearer to her eldest daughter. The house was just eight doors away from her daughter but shortly after the move they argued and are no longer on speaking terms. M5 now says the accommodation is too big for her and she wants to move again. The family have moved several times as mum finds it difficult because of her mental health problems

to stay anywhere for very long. This has caused a lot of difficulty for C5 as she has not been able to establish friendships or maintain them.

Employment/education/training issues
M5 has never been employed and she does not feel stable enough to seek employment,

Finances/welfare benefits/money matters
M5 is in receipt of welfare benefits. Currently she has no debts.

Social and daily living skills
When, well M5 is able to attend to her own activities of daily living. M5 will only socialise with members of her family.

Child 5
Contact with services
C5 is involved in pupil support services, educational support and was referred to Barnardos Action with Young Carers when she was 13. She is also involved in CAMHS.

Presenting problems
C5 has not attended school since year 7. She was bullied by a group of girls which turned into a sexually motivated physical assault. This has had an impact on C5's emotional wellbeing and she has also become socially isolated. C5 is also a young carer.

Caring role
C5 understands that her Mum needs support because of mental health problems. She was 11 years old when she starting caring. Her friends do not know that she is a young carer. She cares for her Mum by doing the cleaning, shopping, providing emotional support and making sure her Mum is safe.

Health and wellbeing
C5 lives a sedentary lifestyle due to her non-attendance at school. She stays in bed for most of the day. C5's relationship with her Mum has been difficult at times, she feels unable to cope with her Mum's behaviour due to her mental health problems. This has impacted on C5's own mental health and she recently found herself being admitted to hospital after taking an overdose.

C5 finds it difficult to access breaks from her caring role without support. As she is not attending any full-time education she is in the home with her Mum all of the time. She is encouraged to attend Barnardos for groups and activities to facilitate both breaks from caring and social integration with her peers. C5 was recently pregnant but shortly after this was confirmed she mis-carried.

Education/training and employment
C5 has attended four alternative educational placements, none of which have met her needs. The placements that are available mainly cater for young people with behaviour problems or who have been referred from youth justice and C5 does not fit in with this group; she is shy and not street wise at all. C5 wants to continue her

education and has aspirations to become a make-up artist. Previously she had been doing well at school academically.

Make a positive contribution
C5 is interested and enthusiastic about sharing her view about issues that affect her as younger carer. She has been involved in awareness rising, through presentations at events locally and nationally. Below is a statement written by C5 when she was 14 that she has presented at a number of events locally and nationally.

What a young carers assessment has meant for me

In September 2007 I had a young carers assessment done by XXXX (carers assessor) from Merseycare.

I was asked questions about my day-to-day life and how I felt things could be improved.

I told XXXX about my Mum's mental problems and how I felt I needed more support so that I could start getting my life back on track. I told her I wanted to do things everyone else my age was doing and that being a young carer often held me back.

XXXX identified me as a young carer and contacted Barnardos children's charity who works with young carers in Liverpool. I started attending regularly. It was great to meet people just like me who are dealing with similar problems. I no longer felt alone.

The assessment was a great help to me and my Mum because now I also receive support.

Barnardos have helped me get back into education again after I had not education for coming up to a year! It helped a lot and they helped me get my voice again.

For so long people have been coming into our home giving my Mum support but nobody ever questioned how my Mum's illness affected me. The nurses would usually come out and ask me to leave the room while they spoke to my Mum, which I strongly think is wrong. Adult professionals need to listen to the family surrounding the patient as there could be stuff the nurses need to know that the patient misses out.

When XXXX came I finally felt listened to and it felt like a huge weight had been lifted.

Before the assessment, I was just another person but finally people looked at things from my point of view and offered help and support.

The young carers assessment helped me so much and if it can do all this for me, I can only imagine what it could do for all the other young carers who are still going unidentified.
C5 - Young Carer aged 14